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# How Can a Focus on the Ethical Notions of Dignity and Respect for Autonomy Help to Improve Healthcare for Elderly People in Islamic Countries?

Abeer Alamri

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HOW CAN A FOCUS ON THE ETHICAL NOTIONS OF DIGNITY AND RESPECT  
FOR AUTONOMY HELP TO IMPROVE HEALTHCARE FOR ELDERLY PEOPLE  
IN ISLAMIC COUNTRIES?

A Dissertation

Submitted to the McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

By

Abeer Alamri

May 2016

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## ABSTRACT

# HOW CAN A FOCUS ON THE ETHICAL NOTIONS OF DIGNITY AND RESPECT FOR AUTONOMY HELP TO IMPROVE HEALTHCARE FOR ELDERLY PEOPLE IN ISLAMIC COUNTRIES?

By

Abeer Alamri

April 2016

Dissertation supervised by Henk ten Have, PhD, MD

The purpose of this dissertation is to identify how can a focus on the ethical notion of dignity and respect for autonomy help to improve health care for elderly people in Islamic countries. An ethic for aging relies on the principle that the losses of age do not detract from a person's essential autonomy. Thus, care should be provided without assuming that older people are different from those of other ages. It is possible to determine that ethical values are similar in Islamic cultures as well as, Western countries. But these values are often neglected when people face the need to provide health care to the elderly people. This dissertation provides a critical evaluation of the current view and application of the ethical concepts of dignity and respect for autonomy in Islamic countries including the ethical challenges that elderly people encounter in health care. The study focuses on three parts; first it will provide a general introduction to the

bioethics in Islamic countries and its relation to Islamic law (Sharia). The argument is that human dignity does exist in the Islamic religion; however, the application and the functions of the concept in elderly health care are disregarded, due to the cultural understanding and interpretations of the concept. This have led health care providers and societies in Islamic countries to miss the momentum of implementing a strong old-age health and social support system that can maintain elderly people dignity and respect for autonomy, and meet their health care needs. The outcomes mandate further examination towards building greater consciousness of treatment and healing, towards the intellectual and cultural adjustment of health practices. The second part presents the applications of both concepts in Western countries, including their functions and meaning. The arguments characterize the notions of dignity regardless of age. It will identify how dignity is associated with respect for autonomy; thus, dignity and respect for autonomy should be a core value in health care practice. The third part analyses the differences and the deficiencies of the application of both ethical concepts to elderly health care in Islamic countries versus Western countries. The arguments will demonstrate how the application of the ethical principle of respect for autonomy in Islamic countries fails to acknowledge Beauchamp and Childress's principle of respect for autonomy. The analysis will help on understanding the major opportunities for and barriers to successful shift in the Islamic countries in regards to elderly health care and the overall process of aging. The challenge is to make sure that all health care providers have the capabilities to convey appropriate care and treatment with respect and appreciation to the elderly individuals' dignity. It will suggest adopting several advantageous approaches that arose in the West and worldwide, and modifying it according to Islamic culture to improve

elderly health care. The results justifies that the notions of dignity and respect for autonomy can help to improve elderly health care in Islamic countries. Concluding that in Islamic countries, a considerable measure of research, education, and preparation are all needed in the sphere of geriatrics to meet today's health challenges associated with the increasing of elderly population. A need for adopting a fresh perception on an analytical gerontology and a respected devoted approach that aims to comprehend ageing process and requirements to change for the better.

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## **Chapter 1: Aging population and the challenges of aging well**

### **1.1 Introduction**

The wellbeing of the elderly population is one of the most important goals of health care services providers. As the elderly population increases the need for care will continue to grow. After 2005, the demographic projections in developed countries imply a significant increase in the elderly population and conversely, a drop in the percentage of a younger population with the social responsibility of caring for this aging population. The projected increase within the elderly number is notable. A majority of elderly people, mainly those in their late sixties and seventies, are healthy. On the other hand, many are not. With each decade that passes and by their eighties and above many of the elderly will become burdened by some chronic disease, disability or both.<sup>1</sup> According to the National Institute on Aging, experience has shown that such changes may be difficult and challenging. However, it also has shown that it is easier to address problems associated with elderly health care sooner rather than later to avoid an impossible situation.<sup>2</sup>

By far, Islamic countries “members of the Organization of Islamic Cooperation (OIC)” have faced rapid demographic shifts in recent decades and fertility has declined steadily in countries such as Algeria, Iran, and Tunisia. In addition to those mentioned, each Islamic country’s elderly population will continue to increase resulting in growing demographic changes.<sup>3</sup> Nevertheless, this predictable transition does not merely involve the size of a certain nation’s population; it also involves a new relationship between generations. On a national level it presents challenges related to health, social, political, and economic structures. Demographic development and planning for a country’s future is

characterized by one important feature, which is to focus on long-term outcomes. According to the United Nations (UN) the world's population will increase in the next two decades from its current level of almost 7 to 8.3 billion, and most of this increase will be in developing countries.<sup>4</sup> Furthermore, a number of studies concur that although the timing and pace of population change varies across the countries of the Arab region, where the majorities are Muslims; the demographic transition in many of these began in the 1960s.<sup>5</sup>

This change is noticeable mainly in the decrease in birth rates, and the increase in life age. Therefore, Arab countries have experienced great changes in the age figure of their populations, and recent increases in the number and percentages of older people.<sup>6</sup> Currently, the proportion of 60 years old and older in the Arab region is estimated to be 6 percent, with projections showing an increase to 17 percent by 2050. Lebanon and Tunisia have the highest percentage of 60 years and more (10 percent and 9 percent, respectively),<sup>7</sup> followed by Morocco, Egypt, and Algeria (approximately 7 percent).<sup>8</sup> Although the Arab region currently has one of the lowest old age dependency ratios (an estimated 5 percent compared to the world average), however this ratio is projected to increase to 8 percent by 2025 and to 13 percent by 2050. This increase will affect the dependency rate for elderly in the area as the responsibility will shift from the support of children to the support of children and older persons.<sup>9</sup> Furthermore, the increase of the older population expected in the next few years in Arab countries such as Egypt, Saudi Arabia, Sudan, and Iraq will pose new challenges for elderly health care as well as family care.<sup>10</sup>

Today, both women and men in Arab countries live approximately 7 years longer than they did 40 years ago, and despite wide variation, a majority of the Islamic countries have current life expectancies between 70 and 79 years.<sup>11</sup> In a survey conducted in nine

Arab countries for Arab population and family, the percentage of older adults with at the least one chronic illness varied from 13.1 percent in Djibouti to 63.8 percent in Lebanon, with the majority of the countries having percentages above 45 percent. Yet resources devoted to the health sector and the coverage and benefits provided to older persons by health care systems in no way match this changing health profile and the needs of medical care for elderly, and the opportunities that frequently accompany the provision of care to a dependent older person suffering from several co-morbid conditions.<sup>12</sup> All these factors are challenging the health care services in most countries and increasing the importance of health interventions.

During the next four decades to 2050, the Gulf Cooperation Council (GCC) will face a challenge with a growing aged population. The increasing proportion of persons 65 years and older, will demand identification of issues facing older persons and how to address them. The following Islamic countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia and United Arab Emirates) have been characterized by a low yet growing population of older persons.<sup>13</sup> The projections for the next four decades show a significantly different scenario because of the change in family growth patterns. Muslim countries will be faced with two vital issues: an increasing proportion of older people and decrease in the working-age population. From 1990 to 2010, those 65 and over accounted for only 2.6 percent of the increase in the region's total population.<sup>14</sup> It is projected to increase to 17 percent during 2010-2030 and to 92 percent during 2030-2050. Thus, the population in all GCC countries is projected to age at an increasing rate, with those 65 years and over increasing to 11 times their 2010 levels by 2050.<sup>15</sup>

Consequently, this increases will require that health services be updated for the

needs of an older population, their security be assured, and provision of proper health services and living arrangements. Living arrangements particularly needs emphasizing because of the significant cultural adjustment it will involve. According to Groth and Sousa-Poza, in Islamic countries the traditional inter-generational bonds will remain strong because of the predominance of Islamic values in the Arab culture, and the joint family system, which has historically been the strength for elder care,<sup>16</sup> however, this will come under severe pressure and burden as a result of the demographic shift. This familial support for caring about the elderly may not be available due to social change, which will be a serious threat to the elderly care support.<sup>17</sup> Therefore, it is the appropriate time to think about the impending dilemma and to take long-term sustainable steps regarding care for the aging population now and to prevent this issue from becoming a major problem into the future.

For all people it is important to have the right to decide on if and when medical treatment is warranted, have their privacy protected, and above all to live with dignity and respect when making such decisions. In spite of this, for the elderly population those rights are often overlooked. Therefore, to meet elderly basic health care needs that have an impact on their daily life, health and wellbeing, this dissertation aims to present an in-depth knowledge of Muslim elderly care in Islamic countries in order to justify the application of the ethical notion of dignity and respect for autonomy for elderly health care in the regions. The discussion will shed light on elements of health services that allow older people to feel they have the ability to preserve their dignity and autonomy. This dissertation seeks to reinforce the applications of the concept of dignity and the ethical principle of respect for autonomy and the perception of the applications in

Islamic countries among primary care providers, care home staff, geriatric care teams, patient advocates, and non-health professionals providing support to older clients living independently, with relatives, in care homes, hospitals, or hospices may also be involved.

This chapter underlines the urge to acknowledge the growing population of elderly in Islamic countries. Firstly, the chapter will explore the global challenges the elderly face. Secondly, the origins throughout history of bioethics and old and in conclusion, physicians and health care provider's attitudes toward the elderly to the development of what are occurring today. Physicians' judgment of what is best for the patient is critical in caring for the elderly. Nevertheless, the patient's personal perspective in keeping with Islamic cultural attitudes and human respect for elderly persons encompass the moral and ethical foundation of human life grounded in the concept of autonomy and/or self-determination.

### **1.1.1 The challenges of aging well**

Population aging signifies one of the accomplishments of human endurance over the last century. Certainly its global effects are appreciated but also significantly challenging because a longer life span must be planned for in advance. An aging population impacts the sustainability of families economically and the availability of health resources for older people. Therefore, it is essential to promote awareness on the global aging subjects and highlighting the importance of scientific research.<sup>18</sup> Awareness is the first step in facilitating the challenges and options of an aging world. It is imperative to assure that elderly people have influence on their own everyday life and grows old with preserving self-determination and dignity.

In point of fact, the global society are ageing not just as individuals but also as a world; in 2006, it was reported that approximately 500 million people throughout the world were 65 and older, and expected to increase to one billion in 2030. Currently, the world is experiencing what some observers have called an age boom due to the rise in the number of people over age 65.<sup>19</sup> Thus, with so many aging and aged populations, societies must take into account of how to provide a decent level of health care for elderly, and what sorts of standards treatments and procedures should be provided.

The National Institute on Aging indicates that the most rapid increase in the 65 and older population appeared to be in the developing countries, which includes Islamic countries. Therefore, countries must rapidly identify the opportunity of the new reality and adjust accordingly.<sup>20</sup> In pre-enlightenment societies, the possibility of death was high at every age and only few people survive. However, in modern industrialized societies, the majorities of people live past middle age, and deaths are higher among older ages. The Hastings Center, in cooperation with the Maastricht Institute for Bioethics reports a country survey on care for the elderly, indicating that indeed the numbers of elderly are increasing rapidly, but also the way countries care for them is a subject that no one will any further be able to easily endure it.<sup>21</sup> The British report describes it as a “demographic explosion,” the German report refers to “fundamental shifts” that will necessitate new structures to care for elderly, and the American report predicts the future of care for the elderly as “dangerous and delicate situation.” An evaluation of the country reports discloses numerous factors that are mainly responsible for multiple problems in elderly care including demographics, the structure of formal and informal health care structures and institutions, the negative social status, and developments in medical technology.<sup>22</sup> Additionally, for many elderly people,



living arrangements symbolize the sociocultural preferences as an example; some people prefer to live alone in their homes while others prefer extended families.<sup>23</sup>

Good aging is one of the critical ethical concerns, it does not merely mean having the good luck and wealth of remaining healthy and active down to the end, but it needs displaying some virtues as long as the individual has the capacity to do so.<sup>24</sup> As stated in William May writings on the ethical life of the elderly “Such virtues do not come automatically with growing old...rather, the qualities grow only through resolution, struggle, perhaps prayer, and perseverance.”<sup>25</sup> Meaning, in order to age well universal virtues are desired by human beings at all ages, and therefore, the old age should be to human standards and not as a distinct species but human beings living human lives, since these virtues need an active development throughout lifespan.<sup>26</sup> Moreover, some of the developed qualities take special shape in the late stage of life such as, wisdom. Thus, the image on aging has been influenced by the idea of what growing old involves, i.e., life span model. This model involves a set of beliefs that consider aging as a process of development through distinct stages, each composed of a set of characteristic features. In spite of all, a human being would certainly not grow to be seventy or eighty years old if this longevity had no meaning for the creatures.

Aging is primarily a mystery that demands us to study the needed behavior towards it. In the Christian tradition the subordinate person in the social order is treated as a moral agent. The powerless are empowered as personally responsible moral beings. Thus, taking old people seriously as members of the moral community means understanding their obligations as well as their rights. So, this may help initiate the long overdue reconstruction of guidelines for moral and spiritual life in old age.<sup>27</sup> One of the

major problems associated with the health care of elderly people is the ethical principle of respect for autonomy; this involves the rights of being fully informed, understanding diagnoses, the right to choose the proper care and treatment, as well as respect for privacy. In addition, elderly person's wishes suggests the person is informed and a level of respect is given as part of any judgment of what is in their best interests should he/she become incompetent.<sup>28</sup> From an outward perspective, these issues may look ordinary and simple, but greatly affect the well being of the elderly, the relationship between health care professionals and the elderly, also it contributes to the overall community within which care and treatment are delivered. Furthermore, a study from the Department of Health and Human Services has showed that older people who are responsible for their own wellbeing and their own health decisions are healthier than people who depend on others to make decisions for them.<sup>29</sup>

In fact, old people are already treated differently, regardless to the fact that adults' rights are not age-related. Therefore, focusing merely on elderly might re-enforce the view that they are unlike others. For health care providers, the ethical responsibilities are equally exercised regardless of who the patient is, but for elderly people certain guidance and assistance is required because of the jeopardy of receiving insufficient care because of the vulnerabilities of being old, the lack of treatment options, and inadequate communication. Additionally, older people are frequently viewed, as stereotypes rather than as individuals, which negatively touch them, they are disregarded in communication, also in many cases due to memory or hearing difficulties health care providers tend to deal mostly with their relatives.<sup>30</sup> This would drive elderly to lack self-esteem and lack maintaining their rights to ask about their health. The General Medical Council in the

United Kingdom emphasizes that a good physician-patient relationship is a partnership based on honesty, trust and good communication, but older people say that they often feel avoided when they exchange their information with the health care professionals. Sometimes, this feeling of being written off is because they are not being told the truth about their diagnosis and options, especially when the information is distressing.<sup>31</sup>

In 2007, in UK the Parliamentary Joint Committee on Human Rights highlighted the issues where older peoples suffer neglect and injustice in health care delivery. Therefore, it necessitates a total cultural change.<sup>32</sup> Up to date, being old can be viewed in various ways; there is the respected leader of a family, the lonely resident of a nursing home, the caring grandmother, the senior manager, and the elderly individual with dementia, etc. In addition, some people worship the old age and admire the timeless teachings they have given, and some others feel pity on them, and criticize elderly for the slow adjusting to the present. So, there is the ideal picture of healthy elderly with energy and strength until the end, and there is the sorrowful picture of a continuous deterioration and dependency, with the results of physical deterioration.<sup>33</sup> Therefore, looking at the interaction between old age and society is a major part of studying and understanding old age. The way a specific society views the attitudes, symbols and practices of old age and conversely, the ways people defined as old, accept, dislike or challenge their assigned role and place are all have an impact on old age. Old people are simultaneously seen as the source of wisdom, knowledge and mystical power and, at the same time, as weak, repulsive and unwanted. Consequently, to live well in this ambiguity of modern aging is conceivably the challenge of our chronology. For instance, Kertzer declares that perceptions on the family and older people has witnessed a swing between the past,

which views older people as securely in control of their lives, treated with respect by everyone, and the modern view, which sees older people moved into institutions, or feel burden to their families due to their weakness and dependency.<sup>34</sup>

Another issue negatively impacting aging well concerns the terminology, which can be crucial. For example, labeling persons as vulnerable, which means that such individuals have no safeguard, and he/she is less likely than others to protect themselves from abused. Community can also give the wrong expectation of the elderly to have the ability to decide for themselves unless there is proof to the contrary. This includes people with mental deterioration who can often make some decisions themselves, even if they need help on deciding difficult matters.<sup>35</sup> In reality, in some way or another all people are vulnerable; illness, disability, grief or other mental distress would yield to being vulnerable, and as people age they feel vulnerable to a host of health care problems. Health care specialists know that good communication and relationships on an individual basis are important for excellent care but these actions are also time-consuming.<sup>36</sup>

In fact, if it is assumed that weakness and deterioration are unavoidable features of age, then individuals who have treatable conditions will not be offered treatment. Older people are less likely to be offered with proper treatment options when their risks and problems are often not discussed with them. Many patients encountering serious illness or entering hospital are facing a power imbalance between themselves and the health care professionals. They may be hesitating to question staff due to the feeling of vulnerability and lack of their rights.<sup>37</sup> Successful aging can be looked at as when aged persons seem not so old and can attribute to themselves a range of activities and goals that suit the social norms of youth. Accordingly, old age can be defined as a well-being and satisfaction and,

therefore, researchers seek to identify the factors that lessen or improve the feelings of well-being and the general positive attitudes towards life, as a sense of well-being and satisfaction indicates a successful aging. Concisely, it is essential to avoid the negative stereotypes, as they are enormously discouraging, especially when combined with the assumption that aging is a sickness and a problem. Indeed, we will be the old people of the future and so we all have an interest in ensuring that older people's rights are well respected. In order to demonstrate how bioethics has an impact on every level of human community, the next part will lay out the history of bioethics and aging.

## **1.2 History of bioethics and older people on history**

In the beginning of human life, aging means growing of the bodies, expanding mental capacities, and developing physical powers. In the middle age, aging signifies improving skills and new perceptions at the same time marginally decline on skills. The President's Council on Bioethics comments that, some people believe that the aging person is continually adding in wisdom and experience until death, and other believer's see aging at the end of life as a total decline of mental and physical capabilities of the individual. But, in the end there is a fact that being human and thus mortal is certain for everyone.<sup>38</sup>

As a matter of fact, aging is a biological, psychological, social, and spiritual journey, it includes viewing oneself in different way as one's life hastens, physical changes, looking back on one's experiences and looking ahead to the upcoming, cherishing life and independence, and accepting dependency and death when they can no longer be fought. Also, it includes modifications of family and social responsibilities such as the obligation to family, work and community.<sup>39</sup> Old age is connected with ethical and survival burdens, a

time when strength and determination start to weaken and when the meaning of survival gives itself with imminent finality, this may prompt that the elderly should not be isolated and should live among the generations. Old age can be a reminder that the young would gain an advantage from the moral example of the old, especially when the next generations live with them such as caregivers, also as receivers of the gifts, which only old age are able to give to the young. Many features; biological, psychological, and sociological factors form the characteristics of the aging experience.<sup>40</sup> Since the dawn of civilization, human begins recognize the progression through the life course, from infancy through old age. The overall progression appears universal, yet the time between birth and death has been organized in distinctive ways by different societies. The simplest concept of the life course has been a division into two stages: childhood and adulthood. But as societies become more complex and as longevity increase, they tend to develop a greater number of life stages. Greek and Roman idea were influential in shaping how we think today about aging and the life course. One of the greatest Greek tragedies an outstanding version is the three parts *Oedipus* cycle, the last play written when its author Sophocles, was nearly 90 years old. In this story, Oedipus became king after he answered the famous riddle of the Sphinx: “ What creature walks on four legs in the morning, two legs at noon, and three legs in the afternoon?” The answer is the human being at successive life stages: infancy (crawling on four legs), adulthood (walking on two), and old age (using a cane as a third leg to support the other two). The Greek medical writer Hippocrates described four stages of life, corresponding to the four seasons of the year. Similar ideas were put forward by the Roman physician Galen and by the astronomer Ptolemy. Ptolemy developed an idea of seven stages of life, which had great influence during the middle ages.<sup>41</sup> During the middle ages, Christian civilization

balanced the image of multiple stages with the metaphor of life as a journey, and no single stage of life could be viewed as superior to another. Just as the natural life cycle was oriented by the recurrent cycle of the seasons, so the individual soul would be oriented toward the hope of an afterlife. The human life course as both cycle and journey was thereby endowed with transcendent meaning and wholeness.<sup>42</sup>

With the coming of *The Reformation* and *The Renaissance*, the ideas about the life course changed into forms we recognize as modern. Shakespeare expressed in his writing, the traditional idea of *Seven Ages of Man*. To Shakespeare the periods of life were mainly roles, acted out on the stage of society. And the role losses of old age appeared as the final act of the play. Thus, a theatrical metaphor replaced the idea of a cosmic cycle or a spiritual journey. At the dawn of modern times, a generation after Shakespeare's drawings and engravings appeared, the stages of life were depicted in a new way. The traditional image of a completed cycle became an image of a rising and failing staircase, where midlife occupied the peak of power. The image promoted the idea of life as a career, in which individuals could exercise control over later life through, for example extended education, good health care and capital saving during earlier stages.<sup>43</sup>

During the 16<sup>th</sup> and 17<sup>th</sup> centuries, the stages of life began to be defined in ways we recognize today. By the 20<sup>th</sup> century, as the practice of retirement became well established, old age became a distinct phase as well. Now at the 21<sup>st</sup> century, it has become clear that human aging is far more ambiguous than might have been imagined in the earlier ages. We can most fruitfully understand old age not as a separate period of life, but as part of the total human life course from life to death.<sup>44</sup> According to Moody, Gerontologists describe aging as "A time-dependent series of cumulative, progressive,

intrinsic, and harmful changes that begin to manifest themselves at reproductive maturity and eventually end in death.”<sup>45</sup> Thus, aging is a communal biological fact for persons and the path of biological aging is different between people, due to the distinct genetic heritage and to the environmental effects that form each person differently from the start to the end.<sup>46</sup> The entire life span might be understood in a way that simply extends, but does not otherwise alter, each life phase, their interrelationships or meanings. The life span could be extended additional years and might be coupled with bodily decline or, conversely, bodily vigor might be prolonged coupled with mental decline. These possibilities require ethical examination and discussion. Accordingly, bioethics has an impact on every level of human development, therefore, the discussion here will further demonstrates that bioethics is itself an interdisciplinary field, that rely on various disciplines and studies.<sup>47</sup> The importance of this part is to present a view of ethics that has a great deal of work on aging subject, also to understand the history of the ethical principles that will be applied to the elderly health care, consequently will reveal the meaning and the functions of these ethical notions in Islamic countries.

### **1.3 Bioethics and aging**

The practice of ethics is grounded in our everyday lives, whether personal or professional, public or private. Because of its roots in philosophy, ethics has developed a reputation for being intellectual, even esoteric.<sup>48</sup> The root of the term “ethics” comes from the Greek term “ethos” or “ethikos,” meaning character or moral. Moral, in turn, refers to the Latin word “mores,” or cultural rules or customs of the people. Culture or customs do not refer to a specific group of people, rather, they make reference to a



generic script for living based on what one “ought to do” as contrasted with what one “prefers to do” or “actually does.” Mores become loaded with meaning when we develop a specific governing system. In this sense, ethics is a marker that helps us measure how close our actual conduct is to an absolute that is defined in terms of the “ought to.”<sup>49</sup> The most notable philosophers in ethics are Aristotle, Immanuel Kant and John Stuart Mill; they all have adopted several theories that can be applied today to bioethical problems, such as virtue ethic, deontology, and utilitarianism. The common scheme used in the analysis of medical ethics is the *four principles* approach postulated by Beauchamp and Childress in *Principles of Biomedical Ethics*. The various theories possess their positive and negative perspectives. Their relevance, application and suitability will vary depending on the situation, culture and beliefs.<sup>50</sup>

Ethics is a dynamic word that includes a process involving means and ends as well as a field of study. As a field of study, ethics has several branches: metaethics, descriptive ethics, ideology, and applied ethics. Some call the first two non-normative ethics, and some consider ideology and applied ethics normative. Metaethics involves raising questions about various ideologies while not subscribing to a particular one. Descriptive ethics refers to the enterprise of characterizing ideologies, also without advocating for a particular ideology. While both are alike in some ways, there is a clear difference in that metaethics is evaluative while descriptive ethics is a matter of mirroring ideas. Ideology is the advocacy of a set or system of beliefs, and applied ethics refers to linking an ideological framework with a real-life situation.<sup>51</sup> In the late 1960s and early 1970s, bioethics started as a distinct arena. At the beginning it focused on the ethical issues related to medical practice, after that it has rapidly expanded to social matters

related to health, animal welfare and environmental concerns. Biomedical ethics covers different ethical subjects and issues from the latest topics, such as stem cell research, physician-assisted suicide, and reproductive technologies to the more ordinary ethical issues for example; elderly care at home, elderly needs, and health care dilemmas.<sup>52</sup>

Although the study of biomedical ethics appeared to emerge within the last few years, however, the codes of medical ethics that guide the moral behavior for medical professions have been existed for ages. In the early 5<sup>th</sup> century, the Hippocratic Oath presents the contemporary ethical standards of preserving patient privacy, treat the sick to the best of one's ability, do no harm and so on. In 1945 to 1949, and after the World War II, ethics of medical research and experimentation established the Nuremberg Code, which helps to provide the current medical ethics standards.<sup>53</sup> Konold stated that the only way of regulating medical professionals and researcher's behavior was the following of the codes of medical ethics and the declaration of the Hippocratic Oath. The Hippocratic Oath has a global influence; it is the central part of a long tradition, and widely used. There are many important questions regarding why it was accepted and is still so widely used as a source of principles for medical ethics nowadays.<sup>54</sup>

Mills' description of freedom is that pursuing our own good in our best, as long as we do not attempt to harm others, or impede them. Every individual is the appropriate guardian of his or her own life. Mill's definition of individual autonomy is the freedom of choice over our own minds and bodies, without the coercive influence of other parties. He puts forth a notion of self-rule such that an individual is free from the interferences of others; this does not entail the freedom to do certain things, but simply freedom from outside interference.<sup>55</sup> Furthermore, self-government is central for Mill, because it is

basic to his conception of a liberal society. On the other hand, Kant's deontological moral theory vastly differs from Mill's utilitarian approach; he shares with Mill a sense for respecting and protecting the autonomy of the individual. However, his moral theory views our moral lives in the milieu of responsibilities and obligations. He argues that morality is dependent on reasons, thus to act morally when we perform actions that are right and required by moral duty. Furthermore he declares, "Act only according to that maxim whereby you can, at the same time, will that it should become a universal law without contradiction."<sup>56</sup> By this he means that an act is moral only if it acknowledges the dignity, the intrinsic value, and the autonomy of persons. Persons are not objects, and though we may inevitably use people as means to our own ends, we must always do so with the knowledge and respect that other persons are intrinsically valuable and equally worthy of respect. Given that persons have self-rules there are unacceptable ways when dealing with them in health care, such as forcing them to act differently than they wish or disrespect their health care decision and wishes. Respect for persons, and recognition of individual autonomy, is a core value in Kant's theory. It also means that one has to behave independently of prejudices, preferences, personal relationships, or self-serving motives. Part of what it means to have reason and will is to be autonomous to be self-governing, or in charge of one's own life.<sup>57</sup> By using others for our own ends or failing to live up to our own potentialities, we violate this autonomy and treat others and ourselves as objects or mere things. These philosophical conceptions of autonomy have contributed in significant ways to our current understandings of autonomy in bioethics generally, and ethics and aging in particular. As some critics have pointed out, the practice of bioethics

has been largely informed by the work of ethicists, who fell closely to the conception of the autonomous that comes out of the philosophical canon.<sup>58</sup>

According to Reich writing in *Encyclopedia of Bioethics*, judgments on individual activity is what defines morality, values are expressions of the cultural structure within which these judgments are made, and ethics are socially derived generalizations induced from individual morality. The healing condition needs special morals as it involves a sick, vulnerable person with a healer who is required to help, and not to abuse the vulnerability of the patient.<sup>59</sup> Within the past couple of decades bioethicists have strongly debated the issue associated with elderly health care. Supporters argue that it is irrational and wasteful to allocate scarce, high-tech health care resources (such as heart surgeries, pacemakers, transplants, and other life-extending treatments) to citizens who may not be healthy enough to benefit from the interventions, and who in receiving such care, will deny the younger population their chance at receiving it. Rather than foolishly avoiding the inevitability of death, the argument goes, we should recognize that there is an end point to our lives at which aggressive, expensive, life-extending medical interventions are not warranted. Instead, we should graciously embrace old age and death, and place our health care resources into life-improving care for older adults (providing things such as canes and walkers, cataract surgeries, hearing aids, hip replacement surgeries, and other life-improving treatments).<sup>60</sup> It is ageist to assume that simply because someone has reached the age of 75 or more years, he/she is not worth the health care and that they cannot benefit from the allocated care. Certainly as the average life span increases to 90 or even 100 years of age, it is more difficult to claim that at 75 years of age one is close to death and has completed all his or her life projects and goals. As the life span

increases, so will our expectations and goals; it will become increasingly unlikely that one will see him or herself as being advanced in age if he/she is likely to live another 20 years and has unfinished life projects, such as traveling or witnessing the birth of one's great-grandchildren.<sup>61</sup>

During the late 19<sup>th</sup> century, Western societies established the “deficiency model.” It is centered on a reductionist biological understanding of the person; thus, it views the aging individual as a continuing decline of one's mental and physical abilities. On the other hand, Eastern cultures emphasize on the elderly wisdom and life experiences.<sup>62</sup> In addition, there is the psychodynamic model, created by Erik H. Erikson who is known for his theory on psychosocial development. The model focuses on the inside disparities and catastrophes, which is connected to the psychodynamic and individual development in life periods. Erikson marks eight sequential life stages; where the last stage shows the struggle between integrity on the one hand, and self-dislike on the other that elderly people face.<sup>63</sup> According to Callahan, integrity involves acceptance of one's life for what it is and the positive evaluation of one's life process. The elderly are a heterogeneous group, having different skills and a series of personal characters and understandings. Thus, any examination of the value of old age accompanied with chronic illness and disability must consider the individual settings, and perceptions. Personal identity as well as subjective self and images are attentively related to biographical experiences, accordingly they are vital for individual realizations of meaning, such as individual life history, which is collection of personal experiences, stories, and interpersonal relationships.<sup>64</sup>

### **1.2.1 The view on aging and the challenges received globally**

Ageism can be use as general statements about a group, which may or may not be based on fact, or generalizing from the group to the individual. Ageism also functions as older persons' invisibility, disregarding, and social rejection. Meaning that older people do not fit the supposed social norm, and they are treated as less valued and less visible. Consequently, their needs and their lives are treated as if they do not matter as much compared to the individuals who are not old and are treated as the norm and the more valued group.<sup>65</sup> In spite of variances in the countries approach when caring for elderly, there is great similarity in the way health care affects the attitude for elderly care in each country. That social care and institutional actions for care of the elderly are extremely insufficient and also not unexpected, in part from negative and poor perceptions of elderly people's needs. Apparently, one could appeal to further clarifications for the poor attention to the elderly, and add that because overall humankind's are not ready to face a hint or an image of destinies that elderly are expecting. In the face of this negative insight of the elderly, some expressions of the social manners reveal a mixed view, and these differ with location.<sup>66</sup>

At the end of 1980s to 1990s, Great Britain for example, suggests a perceptions modification when the media described the elderly as negative stereotype, then later on it shifts the perception to more genuine and positive one. Likewise, in the Netherlands, a caring attitude toward the elderly is notable.<sup>67</sup> In fact, the elderly in many countries are experiencing special privileges, such as the protection of laws prohibiting discrimination based on age, as well as discounts on transportation, utilities, and housing. But these reports also imply an underlying ageism that is not readily agreeable to broad policy

solutions. For example, in spite of a positive view of the elderly the Netherlands reports pressures to “give new generations a chance”; having an elderly person as the head of a business makes one look conservative or lacking in initiative. In sum, the elderly’s social status in the Western countries would seem to be as the United States report describes, “ambiguous and full of contradictions.” Yet, strict approaches can endorse more positive treatment and care of the elderly by younger generations.<sup>68</sup>

In the past, life expectancy for the 40 years old people was 50, but now the average life expectancy has almost doubled, and 50 years old appear somewhat young. In fact, old age has no date; some people choose to be old at there 65, some others possibly at 80. Although, it is essential to keep in mind that older people are not an identical group,<sup>69</sup> they are more likely to be living with disability, unhappy life and many health problems. They often feel isolated, poor social networks, neediness and discrimination due to their age. The origins of many of their problems are social; and most of the time social isolation goes unaddressed. Health and mobility problems increase older people’s feeling of social segregation and the loss of independence; still there are clear relations between increasing age and the need for support, the experience of vulnerability rather than age alone are what defines the older person.<sup>70</sup> Evidently, every patient has the right to be respected and treated as an individual, but older patients are more likely to be categorized rather than treated as individuals, which can lead to discrimination.

Being old creates a different profile as compared with the young and middle-aged. This profile includes the potential for an increase in physical, mental, relational, and professional losses. The study of ethical issues in aging is complicated by the fact that there are individual differences among older adults that come from a number of sources,

from peculiarities in personality to culturally rooted behaviors. Some older adults are strong willed and have managed to be in control all their lives. Others may be willingly submissive because they feel overwhelmed by making decisions. Having recognized that the needs of older adults are like those of others in many ways and different in other ways, we assume that their participation in the community such as their rights and obligations is not any different from that of other members. We would expect them to be much invested in their destiny, to avoid dependence when they can, and to be their own advocates through the life course. At the same time, we would expect them to reciprocate and honor the same circumstances for others.<sup>71</sup> Therefore, when we examine ethical issues in aging, we must view the older adult as a part of a constellation of intergenerational and community relationship bottom up and top down. The older adult's well-being cannot be assessed apart from the community, nor can those in the community detach themselves from the older adult. Therefore, each and every individual in this setting, i.e. the older adult, family, friends, neighbors, and professionals is expected to pursue ethical rights as well as duties in a network of reciprocal encounters. Despite differences in labeling ethical phenomena, we shall begin by framing ethics per se and providing a method for mapping meaning.<sup>72</sup>

In light of demographic projections and epidemiological developments, the demand for care is determined not solely by demographic process but by other social processes as well. The most important of these processes are the values and norms attached to old age,<sup>73</sup> and medicalization, which can be defined as the process by which human existence is increasingly understood in terms of health and disease, and it is characterized by an increasing utilization of medical services decreasing availability of



informal care. This will very likely continue to increase in the coming decades because of the continuous growth of medical knowledge on the one hand and the increasing public awareness of the possibilities of this technology on the other hand.<sup>74</sup> The demographic moves and social developments in Islamic countries have generated new realities in an unexpected growing of the elderly population, such as prompt urbanization, a decline of extended families and scientific innovations make ageing in the Middle East a critical ethical dilemma. A lot of successful measures that promote independence, respect for autonomy and preserving dignity are settled from the medical technology revolutions and community organization, e.g., transportation and physical rehabilitations, assistive hearing and visual technology.<sup>75</sup> At this end, it is necessary to guarantee the best achievable quality of life for the utmost number of elderly.

One of the most important aspects for the well-being of elderly is family ties. The lack of love and caring forces many old people to turn to self-destruction. The availability of informal care given by family members or neighbors also affects the level of demand for medical care.<sup>76</sup> As a result of the ongoing individualization of society and the breakdown of traditional forms of solidarity, the willingness to provide informal care has reduced. Children are moving away from their parents to other cities, having their own families or living alone. They have a more individualistic lifestyle with norms and values that are different from those of their elder parents. Moreover, population living arrangements have shifted from the traditional family to living in institutions.<sup>77</sup> The values and norms attached to old age are also playing an important role in the demand for care. Though the elderly are very often willing to work longer and to make themselves useful for society, they are forced to leave the workforce at the age of 65 or

earlier. In general, the elderly are expected to disengage from society, making room for younger generations. It can be expected that the difference between the aspirations of the elderly, on the one hand, and the unwillingness of society to respond to these aspirations on the other, will result in lower responsibility for health and a decline in subjective health status.<sup>78</sup>

It is undeniable that a society can be judged based on how it manages to take care of its elderly, whether by delivering health care directly in institutions or by supporting home caregivers, eventually, society could show its appreciation to the entire generation. Delivering good care for the elderly is an ethical obligation and it should be provided in an ethical way. Assuring a good care for the elderly is in the interest of both the elderly and the younger generations.<sup>79</sup> A well and comfortable old age, either at home or in an organization would display to the all generations their human potentials, and that they have plenty of time left in life to attain their desires, as well as teaching them the meaning of life and respect. A good old age can present real meaning to the remarkable extension of the life span that medicine now makes possible. Furthermore, a good old age can help on building other balanced model for younger generations. Giving the marvelous technical development with which a 10 years old is more familiar than a 70 years old, it might be true today that the old cannot claim much special knowledge that the younger ones would seek to learn from them.<sup>80</sup>

Some existentialist philosopher used to say “separate me from my body and I am divorced from my community.”<sup>81</sup> In other words, our body helps us to maintain our identity and control of our world, thus we use our feet to walk and our hands to work, etc. and with a move into an institution, the control we have is greatly diminished and the use

of the body is different, because now it is someone else's orbit. The textured world of home becomes a weak world of an institution and a sense of identity is lost. Furthermore, a 93 years old German philosopher name Hans-Georg Gadamer, said, "I am a living anachronism, because I don't belong to this world any more, but I am still here."<sup>82</sup> He indicates that social homes for the aged are perfect sets for rapid aging. Also, surveys were informed by elderly show a similar view. Some Hungarian health providers call them "the places for collective dying"; some others signify them as "houses for the poor or forgotten people."<sup>83</sup> It is well known that a sense of self-govern is connected with several positive outcomes, including a better health status. Therefore, even with the difficulties in delivering care for the elderly, we have to keep in mind that we might all get old and should be guaranteed better situations, thus, it is our integral obligation to be the voice of our community. Therefore, only a good old age can help on restoring respect for the wisdom that can be passed on from generation to generation.<sup>84</sup> A culture of caring for old age is needed in order to have self-esteem, upholding dignity and meaningful human relationships.<sup>85</sup>

Gerontologists and liberal ethicists have claimed that every age has its own aims and no one can decide for another whether his life is accomplished or his natural lifetime has been reached. According to Moody, there are serious fears that an age paradigm will ever be acknowledged in modern society.<sup>86</sup> Truthful information on the conditions and needs of older people is decisive for planning health service development and training of personnel. Given the growth of the ageing population, the need for continuous care will certainly breed, including nursing services and home care.<sup>87</sup> Most Islamic countries have increased emphasis on the importance of improving healthcare. However healthcare

systems in the area have ignored the elderly care needs. The frail and dependent old person will need a variety of professional care, as will their families. The delivery of best care for the ageing population is subject to the understanding of their views and values on end of life subjects. Therefore, it is important to understand that home care and institutional services are complementary. Caring for elderly patients need to be dignified and respectful to their autonomy, also it is a shared responsibility of both families and health care providers. Geriatric knowledge should be part of the education of all health professionals. Also, institutions and living sites should keep in mind the physical needs for elderly people.<sup>88</sup> The final part in this chapter elaborates the duties of health care professionals and their relationship with elderly patients and how these relations changed today.

### **1.2.2 Health care professional duties and the care of older people**

The older medical ethics was grounded on trust between the doctor and patient, but in modern health care, trusting relationships either never develop or never reach a sufficient depth to serve as an ethical foundation.<sup>89</sup> Medical thinking for more than fourteen hundred years was ruled by the writing of the well-known second century Greek physician and philosopher Galen of Pergamum. Muslim translations of Galen had begun by the eighth century, first into Syriac and later into Arabic. By the 9<sup>th</sup> century, 129 works of Galen had been translated into Arabic and were distributed for study and review all over the Islamic world.<sup>90</sup> In Pre-modern Islamic medicine physician-patient relationship drew much of its inspiration from ancient Greece, Farage calls it the “Galeno-Islamic” tradition. Farage provides insight into a world before the biomedical

paradigm, that is a world in which fundamental assumptions about medicine and its boundaries differed radically from those of today. She shows that illness in this world was not the attack of a foreign entity such as germ or virus, but rather the result of some form of imbalance. This imbalance could have several causes, some of which today could be called physical or psychological one.<sup>91</sup>

In this context the pulse was not seen as a mere beat, which could easily be measured by counting; it was seen as the core expression of the multidimensional web of different relations in which the patient was entangled. It was rhythmic, qualitative, and ensouled, therefore the pulse had to be read and understood. It required a perception of the physician-patient relationship that is entirely different from that of today. The physician had to get in touch with the sick person directly without the use of instruments.<sup>92</sup> The relationship between physician and patient was echoic; they mirrored one another and affected one another. The doctor's physical touch when reading the pulse was part of a routine, while in the modern world; this intimate relationship has been transformed into a diagnostic one. Farage argues that this is the result of a whole shift in perception, one that is not entirely desirable.<sup>93</sup> The heart became a pump, no longer the seat of love, anger, and perception; physicians were separated from their patients by instruments, such as the stethoscope, and the pulse lost its music. The pulse was of central importance to traditional Islamic medicine, not merely because pre modern physicians didn't have the benefit of the modern technology, but because the whole paradigm of medicine and healing was different. The history of the pulse then serves as a stark reminder of the changes that have taken place in the world of medicine over the past several hundred years. These changes demand the students of ethics to pay close attention to the historical arguments, and that are the contexts within which

these pre-modern physicians operated. Farage points out contemporary Muslim medical ethics should not focus exclusively on texts from the legal tradition, but should also consider historical, medical, and philosophical texts as part of a more comprehensive discussion of ethical issues in medicine.<sup>94</sup>

Knowledge and skills in geriatric care are essential to physicians' ability to provide high-quality care to elderly patients with chronic conditions. Most primary care physicians will also need competency in several nonmedical processes to practice effectively in the team-based models of geriatric care of the future. Adjusting to the increased prevalence of chronic illness and the relative infrequency of cures requires a change of outlook on the physician's part. Physicians working with the chronically ill elderly have to accept that these patients often cannot be cured, either from their chronic diseases or from their age-related disabilities. For these persons the physician has to be a partner helping to alleviate suffering, treating mainly symptoms rather than causes of their diseases, and being present with patients and their families.<sup>95</sup> For medical decision-making it is often important for the physician to know the patient's individual history, including personal orientations, fears, hopes, and social background. This is especially true in cases that carry substantial consequences for priority setting, for example, in deciding to treat an elderly person with a severe life-threatening lung infection at home rather than in a hospital. In situations that require informed consent, it is important not only for the physician to know the patient's decision and its narrative context; the patient should also be informed about the motives and underlying frameworks of the physician's position.<sup>96</sup> In this respect, confidence, appreciation, and knowledge of the patient's narrative and certain continuity in the care relation are basic requirements for a good care

relationship between patient and caregiver. They also may be inquire to discuss personal aspects of their life or health in front of other people, for example whether they can go to the lavatory by themselves or suffer from bowels problem. Sometimes the questions are addressed to the families as if the older person were incompetent.<sup>97</sup>

In some hospitals, older people are treated in general wards where health providers may have minimum training in caring for elderly patients. Furthermore, geriatrician is often focused on physical problems, so other states such as depression are unexplored. Likewise, the psychological state of a patient's is often not obtained which may extremely affect the quality of life of the older person such as insomnia or declining cognitive abilities. Sometimes this occurs due to the health care provider's belief that these conditions are a natural process and part of aging.<sup>98</sup> Furthermore, elderly people are often the focus of attention for a range of health and social care professionals for a short time in which different activities have to be involved.

In addition, the removal of personal control is linked to the removal of respect. In accordance to Veatch and Fry, part of respect for individual's autonomy is the acceptance of their choices, whether or not the choices are in their best interest. Elderly persons should have the personal liberty to choose and decide their own actions from the available choices. Otherwise, loss of autonomy is often the outcome of the devaluation of the elderly in many societies.<sup>99</sup> Moreover, empowering people to keep control can also increase the dilemmas, such as the degree to which a person has the freedom to take risks. Even though older people are entitled to the same freedom as others to risk their health by irresponsible choices, society often shows a protection or paternalistic attitude to them, even if the individual wishes to remain independent and take risks. Among the typical

scenarios raised by health professionals are cases where older people choose to live independently alone or in an isolated setting, rather than in sheltered housing, after they have had some injuries. Respecting their choice to continue with a risky course of action may shorten their life and encounter additional health care. Nevertheless, it is important that the informed choices of older people are as respected as those of any other sector of the population. Rather than overruling an older person for his or her own good, it is important that families and care providers discuss with the individual how risks can be minimized and reasonable steps be taken to prevent accidents.<sup>100</sup>

Another common causes of serious adverse events in health care are the poor communication between care providers. In particular, communication appeared to break down most frequently when older patients were due to be discharged from hospital or transferred from one type of care to another. Evidence of poor communication between health workers also occurred in hospital settings when health professionals providing specialized care had been informed about the patient's need for treatment but not given relevant information, such as the fact that the patient was blind or suffered from dementia.<sup>101</sup> Research also shows that much of the distress experienced by people with dementia and their families can be prevented when primary care works closely with geriatric nurse practitioners and community and voluntary services.<sup>102</sup> Therefore, working in partnership is the expected norm for many aspects of caring for older people and requires good communication. Many health professionals in Islamic countries at all levels have received little or no training in the care of elderly. There is a need to focus on the need for geriatric education for a wide range of health professionals who provide care to elderly persons in order to meet the current and future demand for care.<sup>103</sup> Physicians and nurses were always



faced with questions about what is right and good for particular patients, and today these questions have become more complicated. The issues upraised by modern technologies and new therapeutic interventions are threatening the moral core of medicine such as the helpful, trusting, and respecting relationship between health professionals and their patients. However, the new field of bioethics is a response to this threat. Health care professionals working with patients need to become familiar with bioethics, and need to make sure that rules and guidelines generated by bioethics are been followed.

This chapter demonstrates the beginning of bioethics and it's impact on human beings. Bioethics as shown in the discussion has a great deal of work on the aging subject. Furthermore this chapter presents the current view on aging and the problem associated with the perception of aging. Thus, elderly lives are viewed with limited dignity or respect for autonomy and with ignorance of elderly sense of wisdom and wholeness. The discourse above also addresses the roles of the health care practitioner in relation to the treatment of elderly patients in the past and nowadays. Next chapter will be discussing the history of Islamic law (Sharia) and its recourses that pertain to the care of elderly. The discussion will move forward to show the current family structure in Islam and in general society views on aging. Also the dialogue will include some of the spirituality roles in an individual's life in a later stage of life.

#### **1.4 Conclusion**

It is not untimely to talk about the globalization of support for older people. The chapter presented the data of rising geriatric populations worldwide and precisely within Islamic countries. The prospect of vast unmet health needs for a growing elderly

population is suggested to be the greatest public health problems of this century. The discussion above involves the trends in elderly care in Arab societies in the context of significant recent changes in proliferation and family formation and composition. Greater attention is needed to meet the growing health care needs of the aging population. Thus, Islamic countries are urged to be able to undergo the growing elderly population and aging transformations. Self-determination and dignity is lost or hidden and it is unlikely that health providers, elderly people, families and communities have a clear understanding or ideas of these principles and how to translate them into a reality. Therefore, the consideration of both concepts of dignity and respect for autonomy are important in guiding the determination of ethical medical care, and health care providers and caregivers in Islamic countries should begin immediate planning to address the ethical issues related to the care for ageing people, and learn from the experience of other countries.

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- <sup>13</sup> Ibid. 70- 73.
- <sup>14</sup> Ibid. 179.
- <sup>15</sup> United Nations (UNDESA), "World Population Prospects," 7-30.
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## **Chapter 2: History of Islamic law and its resources in caring for the elderly**

### **2.1 Introduction to Islamic bioethics**

The origination of bioethics in Islam is a mixture of principles, rights, obligations, and to a certain extent, a call to virtue. Bioethical decision-making in Islam is supported by a framework of values originating from the Quran, the tradition of the Prophet Muhammad (Sunnah), and the clarification of Islamic law. Islamic bioethics explains that the elderly people must be treated with respect and sympathy and that bodily, psychological and spiritual extents of the sickness experience be considered.<sup>104</sup> The bioethics principles and answers to ethical issues have originated from the Islamic legal rulings. Respect for individual dignity, infinity of life, compassion to fellow beings, and relation of a human being with God and the world are the main principles of Islamic ethics.<sup>105</sup> In Islamic countries, bioethics is integrated with religious regulation. New guidelines and recommendations on bioethics were collected and set into practice using Islam as the base. Other monotheist religions, such as Judaism and Christianity, also demand similar ethical principles to Islam, and hence, can contribute to global bioethics. Moreover, the principles of medical ethics introduced by Beauchamp and Childress (autonomy, beneficence, justice, and non-maleficence) are encapsulated in one verse in the Quran;<sup>106</sup> “Behold, God enjoins justice, the doing of good, and generosity towards one’s fellow-men; and He forbids all that is shameful and all that runs counter to reason, as well as malfeasance.”<sup>107</sup>

The word “Islam”, which defines the last of Abrahamic religions, means “submission to Gods will”.<sup>108</sup> Sachedina pleads that Islamic medical ethics is dependent on



Aristotelian ethics and firm legitimate opinions that fail to participate with Islamic normative sources and do not sufficiently meet the ethics of Muslim healthcare.<sup>109</sup> According to Rispler-Chaim, the medicine that is currently utilized by Muslim physicians is similar to that in the West, yet, the bioethics are different. This means that the application of several medical treatments by Muslim physicians will occasionally be conducted according to ethics that have been adopted from Islamic law, rather than by simply medical deliberations.<sup>110</sup> The Quran and the Sunnah stimulated the ethical standard that is now used as the guidance for traditional medicine in the world.<sup>111</sup>

Beauchamp and Childress claim that the four principles of bioethics can be used universally and across different cultures.<sup>112</sup> However, several scholars, such as Padela, Westra, and Bowman, have declared that many Islamic scholars resisted this idea, because these principles are based on Western ethics, and to them, Western ethics have developed into a philosophical science that are withdraw from the religious notion of good and bad. Hence, Western ethics tend to focus more on human reasoning and fact to judge between right and wrong actions.<sup>113,114,115</sup> The principles of Islamic bioethics are closely related to the Islamic Law (Sharia). Additionally, the interpretation of Sharia is based on the collective ethical teachings of the Quran, the Sunnah, and the law of deductive logic (Ijtihad).<sup>116</sup> The main goal of Sharia is to protect humankind utilities or benefits (Maslahah) that relate to this world, as well as to the Hereafter. Inspired by Islamic teachings, Al Aqeel infers that Muslim researchers have suggested some familiar Islamic principles to be considered for ethical decision-making,<sup>117</sup> such as principles of public interest (*Maslaha*).<sup>118</sup>

In general, Islamic bioethics can be separated into two schemes of literature. The

first scheme is applied ethics (Adab), which is an important instrument in describing an ethical tradition that is founded on the combination of the Hippocratic practice into Muslim medicine and moral values. The second scheme describes the Islamic view on biomedical subjects, ranging from reproductive technologies to end-of-life care.<sup>119</sup> In fact, the main principles of the Hippocratic Oath are established in Islamic bioethics. As of 1981, the Islamic Code of Medical Ethics was developed that deals with many contemporary biomedical practices and principles.<sup>120</sup> It is important to note that documents on ethics are distributed through the Islamic system of law (Fiqh).<sup>121</sup> And to eliminate confusion between Fiqh and Sharia; Fiqh is interpreted as jurisprudence, which literally means understanding and comprehension.<sup>122</sup> Thus, Fiqh embodies the articulated legal ruling on a subject matter and the moral value appointed to a specific action.<sup>123</sup> On the other hand, Sharia consists of two elements: the first being physical as the body of legal rulings, and the second being intellectual, as the moral code of Islam.<sup>124,125</sup>

According to Padela in Islamic teaching the Sharia signifies the right way of actions as settled by God, and not just divides actions into obligatory and prohibited, but also mediates between discouraged and encouraged actions.<sup>126</sup> The implications for Muslims' beliefs and moral behaviors are that moral behaviors require faith, and that faith is honest only if it results in moral behavior. However, there is some effort made to differentiate between the notion of moral duty and religious duty. The notion of religious duty embraces both one's duty to God, as well as one's duty to fellow human beings. Muslims believe that God has revealed what is permitted (halal) and forbidden (haram), and it is up to individuals to select whether to follow or reject the direction that God has provided.<sup>127</sup> On the other hands, morality in Islam is comprehended as rules and

responsibilities that derive from the Quran and the Sunnah. Therefore, the distinction of Islamic medical ethics in relation to principlism-based medical ethics lies in the use of a religious base in Islamic medical ethics to determine morality.<sup>128</sup>

Fazlur Rahman, a well know scholar of Islam, specifies that ethical behavior in Islam is stated with regards to divine orders and actions rather than in terms of propositions. He also identifies the primary reason for Muslims acceptance of the Quran as the core of their ethics: Muslims believe the Quran is the declaration of God, and that it covers actual or potential answers to all questions of ordinary life.<sup>129,130</sup> Moreover, Nanji declares that the idea of Muslim loyalty to Prophetic Medicine has often been misunderstood in literature about Muslim medicine, which assert that they promote blind act of faith, and a kind of passive acceptance.<sup>131</sup> Ramadan contends that some scholars debated for the uniqueness of the perception of faith to support curing in their writings. It would be deceptive to prolong this interpretation to the whole field of bioethics and morals among Muslims both currently and in the past.<sup>132</sup>

Although, medical practices and values from ancient times have been maintained, many aspects appear to be customary in Islamic settings, which connected their importance and purpose to a differing set of goals. The shift in Muslim thought of a Prophetic Medicine was an effort to follow with the Prophet's traditions and virtues of human life, while still encouraging the rise of a tradition of scientific medicine. According to Nanji, Prophetic medicine has grown alongside professional medicine, and thus, has cultured its own framework of reference for incorporating thoughts. Prophetic Medicine highlighted the spiritual aspects of healing and the role of faith as a needed component for curing and welfare.<sup>133</sup> Rispler-Chaim alleged that medical ethics is similar

to other ethics, and should always be judged with reference to their place and period. In fact, Muslims typically wish to know the attitude of the Sharia concerning such treatments, and whether Islamic law authorizes such medicine or not, rather than asking their religious scholars whether one procedure of treatment is more effective than another.<sup>134</sup>

Despite this long history, Bella argues that Islamic medical ethics is not well understood, and there is a need to develop a bioethics educational program that is relevant to the culture of Muslim countries. Furthermore, he claims that many medical schools in the Muslim world do not place enough emphasis on the teaching of medical ethics. Thus, the questions of how and what to teach in Islamic medical ethics have not been adequately addressed.<sup>135</sup> According to Brockopp and Eich, currently the majority of Muslims writing on the biomedical issues are physicians who are interested in the medical ethics through their training in the West. But, it is important to keep in mind that the principle of respect for autonomy as an overriding right of a patient initially found its institutional and legal-ethical support in the West.<sup>136</sup> According to Atighetchi, the publications of biomedical organizations should be carefully considered, since controversy between medical opinions and those of the religious experts is common. In fact, legal opinion (fatwa) maybe challenged by other juridical subjects, with new issues challenged by medical ethics potentially resulting in the modernization of Islamic law.<sup>137</sup>

Opposing views maybe seen when there are no well-defined suggestions by tradition, which may lead to the feeling of diversity inherent to Muslim societies. Indeed, Islam distinguishes itself as the complete doctrine originated by the Quran. At the same time, the sharia is the complete law of providing a proper answer to the problems of

humanity at any given time in history.<sup>138</sup> Furthermore, Atighetchi alleged that pluralism is inappropriate to use when describing the current situation, whereas expressions such as “differences and variety of positions within a common religious context” are more appropriate. Islam is the faith of the Quran and if regulated according to the rules of the sharia, doesn’t need any ethical pluralism. The truth and the values already exist in the holy source and only have to be interpreted right.<sup>139</sup> In contrary, many authors emphasize that the sharia is not sufficiently fixed as various judgments can develop and allow sacred law to embrace itself to highly various situations, until they come into disagreement with the spirit of the primary sources. In Egypt, for example, in any debate on bioethics there is a propensity to look towards religion. Many professionals request the assessment of theologians or directly interpret the religious doctrines to provide answers to new bioethical dilemmas. Nonetheless, these can only be based on similarities and not on precise rules, as the holy sources do not indicate modern technologies. Thus, the results of these activities only suggest personal interpretations, which are hypothetically different from each other.<sup>140</sup>

In fact, the majority of Muslim health care professionals have no well-defined idea as to what Islamic medicine is. Even the ones who have an idea may differ in their concept and definition of Islamic medicine. In Islamic teaching, according to Athar, God has implies that every available and beneficial treatment known to us should be utilized, and that if a treatment for a certain illness is not yet known, it is our duty to search for it until we discover it. Therefore Islamic medicine cannot be limited to any branch of the healing arts, which does not have the answer to all illnesses, or at least the potential to have the answer to it. The treatment in question may be spiritual or physical exercise,

surgical procedure, or a combination of any of treatments. Although Islamic Medicine may include, all the qualities of modern medicine, it differs from modern medicine in that it fulfills the following conditions: it is excellent and advanced compared to other kinds of the healing arts; it is a medicine based on faith and Divine ethics; it is guided and oriented; it is comprehensive, paying attention to the body and the spirit, to the individual and the society; it is universal, utilizing all useful resources, and offers its services to all human beings; and last, but not least, it is scientific. On the other hand, contemporary medicine declares these conditions, which is to be excellent, ethical, oriented, comprehensive, universal, and scientific; however, it has failed to fulfill any of them. The second criterion of Islamic Medicine is that it is involved with faith and Divine ethics. All evidence indicates that modern medicine has no faith in God as the Absolute authority and that current medical ethics are by no means Divine.<sup>141</sup>

As a matter of fact, Muslims are divided into two groups; one group is educated and modernized and would accept anything categorized as scientific, regardless of religious or moral analysis, the other group called Islamic scholars who have knowledge of Islam, but not of medical sciences, and they offer their view on everything. However, both groups should be reminded that Islam is not a religion of personal opinions.<sup>142</sup>

Therefore, as a means of protecting elderly people's dignity and autonomy in health care in Islamic countries, this chapter begins with explaining the meaning of bioethics in Islam, and the values of individuals in Islamic societies, especially the perceptions of elderly and their matters in social practices and in moral life. The discussion integrates biological understandings of the aging body with social constructionist views that take bodily experiences to be a socially determined

phenomenon. Thus, this suggests that both biological and social understandings constitute what it means to have an aging or aged body. This dissertation argues for the importance of the application of the principle of respect for autonomy and dignity in Islamic countries, in order to achieve a better-valued health care system that meets the needs and support for elderly patients. The purpose of this chapter is to explain elderly people's rights in Islamic countries, where so far the issue of how to better care for elderly has received little scholarly attention. Islamic teachings on the rights of the elderly have been considered inspirational; however, the practice does not always show such moral attitudes. The following discussion will begin to look at the concept of dignity in relation to elderly health care in Islam, considering older people, as a unique cultural group, with particular ways of being, distinct needs, and discrete strengths. Finally, the issues of spirituality and religion as they relate to later life will be discussed, followed by the cultural perspectives on aging and health care professionals' perspectives.

### **2.1.1 The concept of dignity in relation to elderly health care in Islam**

Human beings are honored by God in Islam,<sup>143</sup> and act as God's proxy on the planet.<sup>144</sup> They are gifted with reason and freewill and therefore are accountable for what they do. Human beings have been given basic understanding needed to differentiate between what is morally right or wrong.<sup>145</sup> In addition, individuals can gain from the world and their own bodies and souls, and every blessing of God in a balanced way.<sup>146</sup> Therefore, everything in the world is considered both a gift and a trust, and due to this, it is believed that we cannot misuse the gift as well as the trust. In Islam, there is an intimate bond between mind and body. In the same way that we need to look after our

bodily health, individuals should also look after their spiritual health. The dignity of a human being extends to his body, and therefore, it is not honorable to harm the human body or treat it with disrespect, including one's own body. This dignity also extends to the time after death.<sup>147</sup>

The key principle of Islamic medicine emphasizes the sanctity of human life that comes from Quran. Thus, when a Muslim doctor is making a decision about patient care, whether the patient is Muslim or non-Muslim, that decision should be in the best interest of the patient. Furthermore, that decision should not just be grounded on the physician's own knowledge and experience, but also has to reflect the Islamic teachings in regards to the situation, without imposing their religious opinions on the patient.<sup>148</sup> According to Holstein, neglecting important features of the moral life and reducing an individual's choices does not serve to support well-being. While we do not oppose making choices, sanction paternalistic interventions, or insist that individuals can function only within a set of commonly endorsed background conditions, we are worried about the moral poverty that a singular emphasis on the language of autonomy suggests.<sup>149</sup> Furthermore, individual choice is not the necessary condition for self-respect. Writing an advance directive or giving informed consent is only a fragment of what it takes to know one's dignity is respected.<sup>150</sup>

According to the Quran declarations, good treatment should be given to the patient's in period of pains and sickness, so that they may get relief and rest as far as possible by sacrificing services and money. Söng and Kim determine that in order for health care professionals to provide care to older persons in ways that respect but not diminish their dignity, there should be an appreciation of elder's strengths won from a



life well lived, as well as an assessment of late life frailties.<sup>151</sup> Furthermore, the authors claim that it is not the job of service providers to dignify or to give dignity to make seem worthy or noble, as this would be a false sense of awarding dignity to another. Rather it is the service provider's, and health care professional's role to respect the intrinsic dignity residing in the individual.<sup>152</sup> For instance, describing dignity in relation to the interaction between capabilities and situations, Shotton and Seedhouse, point out that we tend to lack dignity when we find ourselves in inappropriate situations, such as feeling useless, insufficient or vulnerable.<sup>153</sup> They hold that dignity can be sustained where there are the abilities to respond to dignifying situations, or where the situations are altered so they are not in dignifying. For example, if an older person felt that wearing an open-backed hospital gown was undignified, the person or his/her nurse could either request for a different gown.<sup>154</sup>

One of the reports describing the dignity of older Europeans stated that older people see dignity as a varied concept with the following sectors: dignity of identity, human rights, and autonomy. The data indicates how each of the sectors can be sustained or interrupted by the behavior of the individual themselves, the behavior of workers, and by the environment.<sup>155</sup> Furthermore, a Swedish study proposed three subjects that demonstrate positive and negative features of ageing and vulnerability in relation to dignity. These include the hidden body, fragility and dependency, and internal strength and a feeling of connection. The factual data from the studies provided abounding perspectives from elderly people on their views and experience of dignity and indignity and implies factors that add to or weaken from dignity in practice.<sup>156</sup> Thus, a poor environment of care suggests a failure to acknowledge the worth or value of the patient or

facility user. Lack of privacy for examinations, violations of personal space and humiliation, inadequate access to lavatories, mixed gender wards, and featureless accommodations can cause damage to dignity.<sup>157,158</sup>

In addition, several publications reported that the dignity and the respect of autonomy of older people are often undermined in healthcare settings. Dignity is challenged primarily through negative interactions between staff and patients, a lack of regard for patients' privacy, and a general insensitivity to the needs and desires of an older population. In fact, respect for human dignity is common in all three religions, which states the requirement that we should respect life from its earliest stages, and that we should never take a life.<sup>159</sup> On the other hand, autonomy refers to an individual's control of decision-making and other activities.<sup>160</sup>

Nordenfelt has pointed out that the concept of dignity turns up prominently in a number of international policy statements, such as the Council of Europe's Bioethics Convention (1997) and UNESCO's Universal Declaration on the Genome and Human Rights (1997), and the recent version of the Swedish Health and Medical Services Act (1997).<sup>161</sup> Shultziner has pointed out that, although these documents do not explicitly address the theoretical underpinnings of the concept of human dignity and even offer a standard definition, they refer to a notion of dignity that seems to have meaning insofar as it relies on a tacit or background set of shared intuitions or beliefs. The world has witnessed a remarkable interest in the concept of dignity. For example, in the United States, the concept of dignity has enjoyed a resurgent appeal,<sup>162</sup> from its first report *Human Cloning and Human Dignity*, to its most recent reports *Taking Care: Ethical Caregiving in Our Aging Society*. The President's Council on Bioethics has

alluded to dignity repeatedly in addressing a wide range of controversial bioethics topics.

Furthermore, many international conferences and symposiums were held to deal with the issues and problems associated with elderly care. In 1982, the first initiative to care for the elderly was declared as the United Nations introduced the ninth decade of the 20th century The Decade of the Elderly. In 1983, the World Health Organization adopted the slogan Add Life to Years. In addition, the UN conference held in Madrid in 2002 adopted a plan of action to solve the problems of the elderly in various countries around the world.<sup>163</sup> Prophet Muhammad (peace and blessings be upon him) was a pioneer in this field. He preached the caring for the elderly irrespective of sex, color, or religion, and set a great example in practicing the principles he taught. The Prophet (peace and blessings be upon him) advises the young of the Muslim society to honor the elderly,<sup>164</sup> as they eventually become tomorrow's elderly. Continuous application of his advice helps on bridging the gap between generations and spreads an atmosphere of love and understanding between the young and the old.<sup>165</sup>

Islamic concern for human wellbeing extends beyond the protection of human life and property. It also offers security of human dignity and honor. Islam's view of the welfare of man is that he abstains from everything that is prohibited, and does whatever it has obliged him to do.<sup>166</sup> In the background of human dignity, Muslim jurists arranged their theory of five basic human rights, which is the responsibility of the state to guard. The first of these rights is the protection of life, followed by protection of property, of faith, of honor, and of reason. Basically, honor sustains all the rest, for threat or danger to life, property, religion, and reason are all threats to one's honor. In its more delighted shape, however, protection of honor means the protection of private honor and the family

so that an individual is free to seek his profession. Protection of reason means that the integrity of human conceptual skills must be preserved; that is based on the consideration that it is rationality distinguishes human beings from the rest of creation, so at once a person's reason is lost his or her humanness is lost.<sup>167</sup>

### **2.1.2 The principle of respect for autonomy in relation to elderly health care in Islam**

The ethical principle of autonomy in Islamic countries is far from being recognized as one of the major bioethical principles. According to Brockopp and Eich, medical practice continues to remain authoritarian and paternalistic, thus, depriving patients and their families of any substantial role in determining the pros and cons of a care treatment where ethical dilemmas predominate.<sup>168</sup> Pullman implies that respect for autonomy is vital component of the concept of dignity; however, it should not be involved with the whole of it. Furthermore, it is Pullman's opinion that the significance of autonomy as a value has its limitations "it is a value, not *the* value" and specifies the importance of dignity, specifically where autonomy is lacking.<sup>169</sup>

The concept of autonomy originated from Greek words "autos" and "nomos", meaning "self" and "authority" respectively.<sup>170</sup> Nowadays, autonomy is described as an individual's ability to make deliberate decisions and act up on it. Although there are many theories regarding the concept of autonomy, there is no agreement regarding the nature of autonomy.<sup>171</sup> In general, many experts alleged that there are two main requirements to respect patients' autonomy including giving information about the disease and its treatment, and involving patients in the decision making process.<sup>172,173</sup>

Varelius expressed that personal autonomy should be given as a minimum, and that self-rule must be free from both controlling interference by others and from limitations, such as inadequate understanding that prevent meaningful choice.<sup>174</sup>

In fact, the foundations for Western bioethics is the judgment of what is right and wrong, with a stress on human rights, whereas Islamic bioethics is grounded on responsibilities and obligations (e.g. to save life, seek treatment).<sup>175</sup> Also, the majority of elderly people in health care are dependent on their children; as such, the decision about long term care of the elderly patient goes in practice to the family in most settings. In the context of healthcare, Kara claims that the family is frequently in a place to be harmed, because healthcare decisions can enforce a responsibility of care, emotional stress or high economic expenses on family members.<sup>176</sup> However, conversation between health care providers, patient and family is essential, and therefore, health care providers should be aware of the different kinds of self-recognition and should select the best option of actions for the situation. For instance, in Singapore, the health care practitioners and social workers emphasize that a decision about an elderly person necessitates the family's consent and consultation. This could be accredited mostly to the cultural setting of Singapore. Moreover, Kara claims that the healthcare professional is not the one who will be harmed by the patient's decision because he/she cannot know the values of the patient as the family member.<sup>177</sup>

Bozeman argues that Islamic notions of right do not guide culture, as the West understands them. Islamic culture is identified by the domination of personalism and pragmatism, where dominant authority is coercive almost by definition. Similarly, Max Stackhouse, author of *A recent Study of Human Rights in Three Cultures*, has indicated

that Islam is a religious tradition that is befitting to democratic notions of society. It simply does not present the person with those chances for freedom of action and association that are characteristic of Western Christianity in certain cases.<sup>178</sup> Even Piscatori concludes that respect for life and property, which Islam teaches and its practice of tolerance and fraternity suggest that it unquestionably shares much of the spirit of the present human rights movement. It can also be said that Islam does not improve the basic idea of absolute rights, nor does it avoid differentiating according to sex and religion.<sup>179,180</sup> Furthermore, Kara claims that it is challenging to argue that there is no place for individual autonomy in Islamic countries, because the application of the principle of respect for autonomy can depend on its interpretation. Therefore, it will be essential to discover a more adaptable concept of autonomy that is well-suited with the structure of the culture and with different self-perceptions.<sup>181</sup>

In fact, WHO reported that most Islamic countries, if not all consider familial values to take precedence over respect for individual autonomy.<sup>182</sup> Moreover, Atighetchi has referred to the different utilization of the principles of bioethics. For instance, in Egypt, the autonomy of the patient is reduced, because culture dictates that doctors follow a paternalistic approach. Thus, patients with little education or poor patients are reliant on the physicians to make decisions for them, and worry that if they act otherwise they will be insulting the physicians.<sup>183</sup> In addition, Orbach argues that a countless number of elderly people see physicians as God; thus, they suffered in silence, and would never exchange information regarding their health. Also another issue is associated with treatments that are available to younger patients are withheld, because of shorter life expectancy and such health care decisions are made on the basis of productivity. They

also feel that the young have something to provide to society, unlike the elderly who are seen as a burden.<sup>184</sup>

A significant Muslim Sufi theologian and scholar Mawlana has written several materials, including moral philosophy, the origins of the four principles of bioethics in Islamic tradition, with a different focus on the individual ones compared to the traditional acceptance of them in the Western bioethics.<sup>185</sup> Beauchamp and Childress apply the term “respect for autonomy” to enhance the difference between one’s ability for self-rule and another’s reaction to that capacity. On the other hand, in Mawlana’s writing, autonomy refers to self-rule. He explains that a man is the highest creature of God, has been given knowledge and, thus, has an intrinsic right to choose. He believes that an individual’s decision should be respected if it is made freely with knowledge, and the individual should also undertake the consequences of their autonomous decisions. Thus, in Islam, knowledge (ilm) is fundamental for decision making and therefore, Muslim people are expected to act with knowledge. Muslim people are not allowed to act as they wish; instead they have firm rules from the law to consider when acting.<sup>186</sup> Using Adam’s story as an example, he had fruit in Heaven, which he knew was wrong and showed regret for his action, but his choice and decision was made autonomously, with knowledge and free will.<sup>187</sup>

Accordingly, Mawlana underlines the importance of individuals taking the accountability for their actions. The principle of respect for autonomy can be located in the importance of man as Vicar of God. The Quran declares on promoting of good, “let there arise out of you a band of people inviting to all that is good, enjoining what is right, and forbidding what is wrong.”<sup>188</sup> According to Parks and Wike, the principle of respect

for autonomy requires that each rational and competent individual be given the right to make medical decisions for his or her life. Because each individual recognizes his or her own values, beliefs, and preferences, then each individual should be allowed to decide for him or herself. Currently and for numerous purposes, this principle is considered essential to the good practice of medicine.<sup>189</sup>

McWilliam et al., have specified that the principle of respect for autonomy is endangered when patients and their caregivers are not given enough information or do not fully understanding their diagnosis, and cannot make informed choices concerning their care. In particular, elderly people can easily become disempowered in healthcare settings.<sup>190</sup> The history of the importance of respecting patients' autonomy goes back to Nuremberg codes of ethics and the Helsinki declaration.<sup>191</sup> The principle obtains many interests during the last decades, such as the International Medical Association (IMA), which alleged that patients not only have a right to obtain necessary medical information, but they also have the right to choose the best treatment available.<sup>192</sup> Health care professionals' duties are to respect patients' autonomy, while promoting their health. In elderly care, there are many cases where the health care providers may take a way a patient's basic needs. Therefore, healthcare providers must respect patients' autonomy, provide the needed information, and involve elderly patient in the process of decision-making.<sup>193</sup>

In brief, Islamic principle does not present a concept of the rights of the individual, and these rights do not attach to mankind. Therefore, in regards to the principle of respect for autonomy of elderly patients, they are respected, but only in a way that the culture feels or understand this concept. This means that taking care of the



elderly is respectful, and a misunderstanding of that respect can result in an individual feeling disrespected.<sup>194</sup> Most of the decisions are made by the adult children, such as which hospital to go to, and/ or what treatment to have, where to stay and whom is taking care. Consequently, in Islamic countries, the family continues to play an important role in handling the illness and care for the elderly patient. Moreover, Atighetchi verifies that the principle of respect for patient autonomy, which involves informed consent and many other concepts, should be adapted according to different local, cultural, religious and national realities.<sup>195</sup>

Additionally, autonomy continues to mean self-directing action, which is symbolized and enacted by the process of informed consent. This view, however, is far thinner than what a robust approach to aging requires. Autonomy is often reduced to making choices, with no consideration of the impediments that make such choices difficult, if not, in some cases, impossible without an availability of options, or the presence of meaningful life choices, we fail to provide for our elderly in ways that are significant and meaningful for them. Respect for autonomy thus means more than removing barriers to and honoring choice. Personal autonomy requires much more than unforced choice. The goal is not to eliminate autonomy from ethics and aging, but to alter the understanding of autonomy that is typically invoked in connection to the elderly. Respect for the choices and values of older persons are important, especially in the face of a culture that has largely denigrated the elderly and reduced them to the status of children.<sup>196</sup> The way in which autonomy is defined and understood, however, affects the health treatment of these individuals. If a concept of autonomy is to serve such persons, then it must be couched in a moral language that finds some fit with their actual experiences and capacities. The contradiction is that the original

concept of autonomy includes a view of persons as healthy and independent, whereas the reality of elderly care shows individuals that need support and participation, which appear contrary to this ideal.<sup>197</sup>

## **2.2 The meaning and values of elderly care in Islamic countries**

In Islam, life as one of the greatest gifts of God has a great value and is irreversible. Therefore, it must be valued and protected even if it has a poor quality.<sup>198</sup> According to Daar and Khitamy, Muslims may see illness as a test from God, but it is not regarded as a punishment or madness of God.<sup>199</sup> Hence, it is essential for the patient to look for treatment and to prevent the feeling of being hopeless. For Muslim countries' tradition, respect for the older is commonly stated as "water belongs to the younger, word belongs to the older." This is a frequent saying that summarizes the relationships between people, where *water* symbolizes humanity and care and *word* symbolizes decision-making.<sup>200</sup> In Muslim culture, the ranking in the family is between parents and children and is considered very important. It is inappropriate to talk about older individuals outside of the family without using a title of respect. In general, caring for elderly patients takes place at home and placing them in a nursing home is limited. The family is the one who measures and evaluates the harm and the ones who decide whether to undertake such medical treatment for the elderly patient. However, in today society old age is devalued in many ways, and elderly people are seen as major social problems rather than as people who can deliver wisdom.<sup>201</sup> Today's thinking and attitude are that our lives have a meaning only by our own values and actions reduces and conceal the feeling of wholeness. Therefore, elderly individuals have nothing to give, and this

devaluation of the aged has formed an obscurity. On the one hand, life should be saved and extended through medical technology; however, on the other hand, life is not viewed with either dignity or respect for autonomy.<sup>202</sup>

Islamic teachings include an ideal way to respect the elderly, particular the parents. In Islam, respectful behavior and loving devoted service to the parent is a must. As is stated in the Quran, next to Allah and the Prophet, comes the respect and dignity of parents. Also, as declared by the prophet Muhammed, the father is the main gateway of heaven, whereas heaven lies beneath the feet of mother. Much importance is given to fulfill the rights of parents in general and at their old age in particular. Furthermore, in the Quran, parents are declared with appreciation and respect eleven times.<sup>203</sup> Therefore, it is necessary for children to serve parents especially when they attain old age, because their condition is liable to deserve sympathy. Due to old age and weakness, the strength and energy to walk and work or earn money is extinguished. Also, the elderly experience difficulty, as vision and hearing become weak.

The way people see themselves has several dimensions, including personality, self-esteem, body image, and social roles. The aspect of self-concept that changes the least with age seems to be personality. For instance, an extroverted person, one who enjoys interacting with other people, is likely to remain extroverted from childhood into the final stage of life. An older person who is skeptical or gullible is likely to have been that way all along.<sup>204</sup> Other aspects of self-concept, in contrast, do tend to change. However, the aging mind is not so much the impetus for change as is the progression of circumstances in which people find themselves. For example, the image of one's body changes as hair becomes grayer and skin gets more wrinkled. Furthermore, self-esteem

varies throughout life with one's successes, whether they are interpersonal, occupational, intellectual, or otherwise. Orbach argues that a weakened body does not mean a weakened mind, and such treatment will only be positive if we are capable of articulating respect for the elderly patient as having lived along life with extremely fast change, and as having been gifted with enough wisdom to endorse a balance of power between themselves and today's generation. We need to be open and humble enough to learn from them, as much as they can learn from us.<sup>205</sup> Social relationships in old age tend to exhibit the most predictable types of change. For one thing, people's social networks become smaller as time goes on, and sometimes with retirement, work relationships diminish or disappear.

Gerontologists have spoken about the late-life transition as a matter of role loss or role discontinuity, which is another aspect of self-concept that changes with age. Growing up and growing older, we leave behind earlier roles, such as child, student, employee, parent, and perhaps, spouse and friend. In earlier-life transitions, role losses are typically accompanied by new roles that take their place. Ceasing to be a child in one's family of birth, growing up and takes on the role of parent are examples of earlier life transitions; however, in old age, some roles such as those ended by widowhood or retirement, may never be replaced, even if old age has a central meaning to what we recognize to be life fulfillment or morale in old age. If the deeply held value of old age is threatened such as the wish and need to be independent, or to be socially respected, then both the individual and society will try to avoid age and deny it as much as possible, and such denial of aging is a crucial problem for any society.<sup>206</sup>

Gerontologists frequently use the expression normal aging to define the irreversible process that is a feature of each species. Aging can be defined as a time-dependent series of increasing, advanced, and hurtful changes that begin to be obvious at reproductive maturity and eventually end in death.<sup>207</sup> The awareness of normal aging is essential because health care professionals generally see sick people; in that event, it is easy to develop negative views about older people. One common stereotype describes older people as weak and sick. But, in fact, the majority of people over age 65 are healthy enough to be involved in everyday activities, such as showering, clothing, or preparing meals.<sup>208</sup> Although aging is not in itself a disease, with increasing age comes increasing vulnerability to sickness. The vulnerabilities of old age are the specialty of geriatrics, and this subject is important for health care and humanity.<sup>209</sup>

A study discovered that the greatest threat to well-being in old age is the loss of life meaning and hopelessness, not the fear of poor health. It has been shown that people discover value and meaning in many ways: job, leisure, grand parenting, and relationships. They also stated that unless they were sick or miserable, they didn't feel old.<sup>210</sup> For example, urinary incontinence in old age, which is a matter of global concern, causes severe restrictions on elderly people's social life, as they are incapable of going to public places to work or socialize for longer times with family or friends. Due to the restraints placed on their daily lives, elderly patients with urinary incontinence have poorer perceived health, and this has a considerable negative impact on their quality of life,<sup>211</sup> which in turn may lead to depression. This, in fact, has posed a larger problem among Muslim population, which involves their abilities to do Islamic prayer. The majority of the elderly indicated that the practice of religion is the main spiritual need.

Thus, the connection of religion and medicine offer significant attention to the ways that religious involvement or beliefs shape reaction to illness, or health outcomes.<sup>212</sup>

Thus, Siddiqui states the importance of maintaining the individual's dignity, and relying on spiritual strength when caring for the aging,<sup>213</sup> and to be interrupted from practicing religion for any reason, causes a great emotional and psychological burden on old age.

Additionally, the majorities have stated that their spiritual desires have increased with age and therefore, it is a huge concern that these increasing needs are not being met.<sup>214</sup>

The thought of whether old age has meaning relies on two basic components; continuance of midlife values into old age, and realizing some new challenges that fits the last phase of life. Beauvoir considers that only continued activity on behalf of new goals will give our lives meaning, whether in old age or at any other time of life.<sup>215</sup> Along these lines, Rowe and Kahn's approach of successful aging suggests a way of maintaining meaning by adjusting ourselves to diminished reserve capacity. Rowe and Kahn believe that success is well-defined by enhancing capacity for continued engagement with the activities of life.<sup>216</sup> It appears ironic that innovation has made it promising for people to live a greater time of their lives in old age than ever before in history. At the same time, the idiosyncratic view of postmodern culture leans to exclude finding any special meaning or purpose for the last stage of life. Nevertheless, the future of an aging society will be formed by all of us because, in the end, the old are basically our future selves.<sup>217</sup>

Additionally, there is a common stereotype that older people take longer to learn new things, and this is a stereotype that turns out to be true. Compared with younger people, older people do tend to proceed more slowly in new learning situations. This

slower speed is partly explained by lack of practice, differences in learning style, or motivation. Chronological age doesn't explain much about learning ability; thus, in any case, slower speed or reaction time usually isn't a factor in everyday performance. For example, short-term memory may weaken, but it usually doesn't seriously affect daily life. Along with the stereotype of low creativity, there is a common assumption that older people, overall, are just plain bored. Another stereotype suggests that older people cannot adapt to change; yet, a little reflection shows this stereotype to be wrong.<sup>218</sup> The vast majority of the population undergoes enormous changes that most people are likely to face in their later years, such as retirement, widowhood, adapting to chronic illnesses, and so on.

Islam emphasizes preserving one's health and avoiding illness, but when prevention fails, all efforts must be made to restore health. One way of saving lives of people is to treat them when they become ill. It is a joint duty of the patient and health care professionals or society in general. Thus, seeking treatment is a responsibility for the individual himself, and everyone in the community is needed to support the patient in treatment. Curing people is considered a blessed job, and the doctor must do his best to cure the illness, but at the same time he must know that the actual healer is God.<sup>219</sup>

With the increase of the aging population in Islamic countries, especially the oldest who are expected to have multiple chronic disorders, the demand for continuous health care facilities will certainly increase. This need will have to be met with more nursing services and homes or community-based long-term care. Today, many older people are healthy and independent; however, as in other countries, some will have physical and emotional disorders. These difficulties produce a population of older people vulnerable to losing

their ability to act independently and at danger of becoming fragile. The nature of the needs of this population causes challenges for healthcare providers. Beyond severe and episodic health problems, the older person may have numerous chronic health problems that interface with social, emotional, and environmental concerns. A growing geriatric population, with increasingly unmet healthcare needs, strongly implies the need for better educational training of those health professions that actually or potentially serve this population.<sup>220</sup> In Islamic countries, the lack of sufficient numbers of skilled geriatricians seriously challenges the ability of the elderly having adequate access to healthcare, treatment, and care. This may also lead to avoidance and neglect of older people and their difficulties. Moreover, this deficiency leads to improper care, vulnerability and poorer patient outcomes. Education is the core for solving the negative thoughts and attitudes toward older people.

### **2.2.1 Cultural and familial perception of elderly care versus elderly perception**

For many older people, the effects of chronic illness and the social devaluation that accompanies frailty and inactivity threaten their self-respect. According to Taylor, social devaluation threatens our dignity at its most fundamental level. But, along with our profound need to feel respected, is a need for a framework that shapes our conception of the good in the absence of which our life is spiritually senseless.<sup>221</sup> It is this sense of making qualitative distinctions that some way of life is infinitely higher than others that becomes increasingly difficult when we become old in societies as diverse as the ones in which we live. Extant cultural norms give little or no guidance once we become frail. Yet, this search for a viable self, for recognizing and having goods that express who we



are, even in conditions of frailty and dependency, is essential for remaking our identity. Morality is thus far more demanding than granting individual rights to make choices that may not have any connection with their deeply held values or beliefs.<sup>222</sup>

The aging and aged body has largely been devalued and feared because of its associations with frailty, loss of control, and death. In a youth-obsessed culture that hyper-values vigor, and good looking youthfulness, reminders of youth's fleeting nature are not welcomed. For older women, meanings attached to living and functioning with bodies that are not culturally esteemed receive almost no public attention. Because old women inhabit and live in and through culturally stigmatized bodies, they are usually acutely aware of their bodies as both material and constructed, even if they do not use these words. And they are aware of how others judge their bodies, including their old age peers. How we experience our aging bodies is complex, and influenced by many forces, such as, cultural forces and the myriad interactions that occur in the overlapping and discrete contexts in which we live. These forces and interactions shape our embodied selves. Bodily deterioration poses threats to our identity and integrity as we witness others reading the texts we call our bodies. Some commentators on the aging body take what we consider to be a strong social constructionist view: that the process of aging and the experiences of an aging or aged body are socially constructed and not biologically given.<sup>223</sup> Certainly, cultural expectations that one remain youthful, vigorous, attractive, and physically fit, all affect how individuals understand and see themselves. In truth, these cultural ideals inform our very identities. Gullette states, "The basic idea we need to absorb is that whatever happens in the body, human beings are aged by culture first of

all.”<sup>224</sup> In a similar vein, Overall claims that old age is socially constructed and culturally variable.<sup>225</sup>

Muslim culture safeguards respect for the elderly and highly values the bonds of care between all the family members. The elderly people are regarded as a source of religious faith, spiritual blessing, wisdom and love. Yet, despite the overall feeling among many people in the region that referring an elderly parent to a nursing home violates the sense of sacred duty towards them, today many individuals are faced with situations, in which there are no alternatives. It is well-known that the majority of elderly people in nursing homes are there due to circumstances where their families cannot possibly take care of them. Among such groups are those whose families are overseas, single women, old people whose families cannot support them financially, and those who suffer from illnesses where continuous professional care is needed. In reality, morbidity patterns have changed and have resulted in extended conditions of chronic disease, dependency and loss of autonomy for larger numbers of elderly in the Islamic countries.<sup>226</sup>

For instance, the elderly of Bangladesh are usually taken care of by family and society. However, with development and globalization, this traditional support system is gradually weakening. A strong plan is needed to face the challenge of aging and the future support burden of the old, because the continuing process of having a nuclear family will add more burdens on the elderly support system. Thus, these kinds of social changes along with the economic suffering will be very dangerous to the elderly support system of Bangladesh. Thus, it is the right time to consider it and to take long-term supportable aging strategies to face the future problem.<sup>227</sup>

In fact, elderly people have some privilege in Islamic country, as it was recommended in the Quran and hadith; however, when it comes to reality, it's not always applied. In Islamic countries, children are responsible for taking care of their elderly parents, meaning that the elderly person has no right to decide where to live. In many cases, after admission to the hospital, the physician discusses the situations with the family, while ignoring the patient. Also, in other cases, the older person keeps moving from one house to another, spending time between his children's houses. Most of the time they feel vulnerable and follow whatever their adult children decide. Nowadays the traditional family support structures for the elderly people are declining, and the challenges are becoming more complicated. In traditional societies, nursing services that are designed for elderly people are not accepted culturally. Thus, having known this important aspect of the complex system of the care of the elderly, it is reasonable to admit that elderly home cares and similar long-term care services have a role to play in today's societies. In fact, institutions for the elderly people in Islamic countries do exist, however, the activities for authorization and continuation of standards of elderly homes and nursing homes are inadequately and badly developed in the region.<sup>228</sup>

One primary feature of Arab countries is a social culture based on Islamic values and principles, shaping a well-defined intergenerational support system. Prescribed by the Islamic code of conduct, promoted by stakeholders and the law and internalized by the individuals, the family continues to be the cornerstone for the support of older people. Yet, family cohesion cannot be assumed as secure in the face of new demographic, social and economic realities, as well as emerging health needs, undermining its efficacy and efficiency.<sup>229</sup> It is important to note that while some cultures explain obligations to

elderly parents primarily in terms of duty such as in Islamic countries, other cultures explain them primarily in terms of affection. Because parents give life to their children and take care of them until they are adults, children owe their parents a debt of gratitude and are obligated to take care of their parents when their parents can no longer take care of themselves. To fail to take care of one's elderly parents is shameful and, in many instances, enough to warrant society's condemnation.

Islam preaches affection and responsibility between members of the Muslim family.<sup>230</sup> Family ties in Islam are based on clear stratifications of the rights and duties of every individual family member and are designed to shrink injustice and encourage compassion and charity to the powerless. More specifically, the religious commandments engage believers in a clear child-parent code of behavior, by emphasizing the duty of children to obey their parents, and to support and shelter them in old age.<sup>231</sup> Moreover, Islamic teachings emphasize affection, honor, and respect for parents and older members of the family, comparing respect for elders to the honor offered to God.<sup>232</sup> Because this moral code has impregnated the social culture and influenced the patterns of old-age care, Arab people age in their homes, surrounded and supported by their offspring. Co-residence is a primary means, by which Arab families meet the needs of older adults. In most traditional Arab societies, the elderly live in extended, multi-generational households and rely on their adult children, their spouses, and other family members for material needs and personal care. When the health and economic status of the older parent declines and the need for assistance with activities of daily living increases the direction of care is naturally reversed.<sup>233</sup> Yet the arrangement is still viewed as mutually beneficial by both sides: caring for a disabled parent is not regarded as a burden, but as a

natural extension of family life. In fact, caregivers often reap a personal sense of reward and satisfaction from fulfilling familial and religious obligations towards the aged and see the opportunity to attend to the needs of parents in their latter years as a gift from God. These family norms that dominate in the Arab culture explain the low rates of institutionalized older persons in the region, in which nursing homes and old-age institutions remain the last resource for poorer families.<sup>234</sup>

Nevertheless, in the Middle Eastern context, the feminization of ageing, although a well-recognized phenomenon worldwide, is uniquely affected by culturally oriented traditions of son preference and gender bias practices throughout the life course that contribute to the vulnerability of women in their old age. These practices not only leave women in need of social, emotional, financial, and medical care in old age, but also increase their reliance on informal sources of support.<sup>235</sup> The implications of these practices are clearly reflected in the gender differences among the various attributes of Egypt's ageing population for example. In the 2006 census, more than 88 percent of older women were illiterate or unable to read and write, in contrast to only 70 percent of men. These general attributes of older persons, and older women in particular, clearly affect an individual's welfare, and health support. One major critical issue in the life of the elderly is health status and access to health care, but in Egypt, information on the older population's health status is extremely limited. One recent comprehensive study of older persons' health status and access to health services in the Ismailia governorate, however, did show that although women usually outlive men in Egypt, older Egyptian women are more likely to have a worse health status than men of the same age. This difference is evidenced by the higher number of poor health self-ratings among older women. Gender differences in health status

were also observed in older persons' self-reports of physical limitations and disability. Women 60 years of age and older tended to experience more limitations in their activities of daily living and in both their upper and lower extremities compared to their male counterparts. Yet, even given these striking gender differences in the ageing experience, Egyptian society continues to maintain a strong conviction that the ultimate responsibility for older persons rests squarely within the family. Until now, therefore, there has been little progress in formulating a national policy for older people. As a result, the needs of the older population must still be addressed.<sup>236</sup> At the same time, the rapidly aging population and ongoing social and economic changes resulting from current demographic trends will render most traditional sources of support inadequate to meeting the needs of the rapidly increasing ageing cohorts. Solving this problem will require the adoption of new strategies that can better secure health and quality of life for our ageing population and enable older individuals to work and live independently in their own communities.

In Muslim countries, the patient is first and foremost a member of the family, which feels responsible for him. The consent of the elderly ill and/or an incurable patient is easily taken over by the family in order to avoid emotional problems for him. Thus, avoiding any negative consequence for the patient at the psychophysical level caused by learning the truth is preferred, even at the price of lies and concealing the truth. For the latter approach, both medical paternalism and the protective role of the family are indispensable instruments. In Pakistan, for instance, both doctors and family members opt to conceal the truth from the patient, if the news is considered psychologically damaging. Doctors are not very willing to discuss the pathology, therapy and diagnosis with a patient, especially if they are seriously ill.<sup>237</sup> Amongst the causes taken into consideration

are the importance of numerous families with strong internal bonds, the fear of creating incomprehension, a general sense of impotency and despair in the case of a tumor and anti-tumor therapies, and the cultural level of the patient. A Muslim society is strongly protective towards a seriously ill patient.

In this context, as a general principle of Islamic teachings, family and community needs take precedence over the individual needs. In fact, in Muslim culture, as in many other cultures, the provision of support for an aging family member typically involves the entire family rather than the efforts of any one individual. Thus, in Islam, it is a common cultural imperative and expectation that a Muslim's honored duty is to lovingly and happily care for his or her parents in their old age.<sup>238</sup> For these reason the doctors prefer to communicate with chosen members of the family. In Egyptian and Saudi culture, the situation is very similar, where the authority and the unity of the family exceed the importance of the autonomy of the single individual. An elderly patient's decisions are easily changed by the family's desire to protect him. Similarly, the family expects to be the first to know the bad news concerning the patient. Subsequently, the family decides if and how to tell the patient. This can obviously create difficulties for a doctor wishing to disclose the serious truth to the patient. In Turkey, with some exceptions, it appears widespread practice not to give the patient directly specific information on negative diagnoses and prognoses. According to the regulations, a fatal diagnosis may be revealed to the patient only with great caution; if the patient is not opposed, the family will be informed of the diagnosis. The "do no harm" and "beneficence" principles appear to take priority over the principles of autonomy in Turkey and may represent the basis for hiding the truth from the patient. Therefore, in Islamic countries, medical paternalism is based

on social structures and values deeply rooted in society. Requests for information by the patient and the desire to actively participate in decisions are limited. The patient wants the doctor to be the expert and competent authority. This attitude is often accompanied by a “fatalistic world view” by patients, an approach generally associated with Islam. Nevertheless, it would appear that the attitude of Turkish doctors is increasingly open to direct disclosure to the patient.<sup>239</sup> The protective attitude of society and the family to the seriously ill or terminal patient is accompanied by the paternalistic role of the doctor. Nevertheless, the trend by doctors to inform the patient of his state of health is gaining ground everywhere.

Although the Quran does not directly deal with how to care for aging parents, the prophetic teachings emphasize the children’s responsibility to care for parents, as they were cared for as infants. Traditionally, families and religious leaders have interpreted this as a duty to care for parents at home.<sup>240</sup> The parent-child relationship is structurally harmonizing. Parent and child in Islam are bound together by mutual obligations. However, sometimes the age difference is wide and parents are grown old and might be physically or psychologically weak. This condition is often having the features of impatience, deterioration of activities, sensitivity, and misjudgment. This may also result in abuses of parental power and nervousness. According to Söng and Kim, due to these concerns, Islamic religion has been aware of certain facts, thus made basic requirements to rule the individual’s relationship to his parents. Parental rights seem to be considered in such a way as to reduce to a minimum the possibility of conflict. This is probably best indicated by the fact that the parental rights come second only to the highest value, namely faith in God. Also the same indication is restated in the Prophet’s declaration that



what pleases one's parents is also pleasing to God, and what annoys them equally annoys God.<sup>241</sup>

In addition, developing countries with small percentages of elderly people and with expectations for an increase in elderly population could learn a lot from the experience of developed countries in matters of health promotion and care models for the elderly. Care of the elderly is somewhat family dependent, especially for the spouse or daughter of the elderly, because Turkish culture still depends on paternal authority and family loyalty. Although family structures are changing mainly in big cities, children are still expected to care for their elderly parents, especially if they suffer from dementia or have a stroke.<sup>242</sup> The problem occurs when cultural norms do not allow people to place their relatives in nursing homes or homes for the elderly. Nursing homes and homes for the elderly are present in many cities, although usually not equipped with good quality facilities. However, the problem of family dependent care of the elderly can be turned into an advantage if the family support can be coordinated with home care programs for the elderly, with the cooperation of government and health-care departments of nursing, and geriatrics. Private home care systems are also inadequate and exist only in a few big cities. Social care systems, domestic and personal care, day care, night care, nursing home, and family support systems are not sufficiently present in Turkey.<sup>243</sup>

Turkey, with its bridging role between Asia and Europe, stands as a potential candidate model for developing countries' of elderly health strategies. Although the traditional family has been changing gradually, especially in the large cities, to a modern type, and the number of elderly people who live alone has been increasing for the last 10 years, care of the elderly is still mainly provided by families. Being old in a young

population such as Turkey seems to be somewhat discouraging for the elderly and health professionals in the field of geriatrics. On the other hand, elderly people in Turkey have many advantages offered in the form of traditional family support and feeling valuable due to respect from others.<sup>244</sup> Also, Ankara Municipality has a daycare system for the elderly, which provide visits to homes and help with elderly people's medical and social problems. Well-trained professional staff that are knowledgeable in the care of the elderly, such as social workers, specialized nurses, occupational therapists, physiotherapists, geriatric psychiatrists, and geriatrists, are present in big cities, but cooperation, organization, and the number of staff are not yet adequate.<sup>245</sup>

Nevertheless, in the wake of a quickly changing demographic scenario in developing countries, the need to meet the challenges ahead to account for an increase in the absolute population of individuals aged 65 years and above cannot be underestimated. Particularly, in Arab countries, old age dependency burden is likely to increase. Unfortunately, most of the countries in the region are not anticipating the seriousness of the problems likely to crop up in the future due to the sheer increase in absolute numbers of the elderly population. The biggest challenge for countries with limited resources to overcome would be to meet health care needs and housing of the growing population of their senior citizens.<sup>246</sup> The former refers to ageing of populations in the aggregate sense in which age-sex structure of a population, represented by the age pyramid, undergoes a change as a result of ageing. According to Saxena, the assumption is that there seems to be no immediate threat to the elderly in their living arrangements in Arab societies where old persons are respected, loved and cared in their families.<sup>247</sup> However, ongoing social changes due to diffusion of Western culture may have some implications on traditional

social support systems. This, in turn, may significantly affect traditional living arrangements in the long run. An increase in nuclear living arrangements among the young generation and the diminishment of the extended family system are likely to weaken family care and support for the elderly. In the absence of proper care of old persons in their family, some would require to shift to nursing or old age homes. Enhancement of self-reliance of old persons is crucial to facilitate their continued participation in society. Necessary programs should be developed to enable elderly people to lead self-determined, healthy and productive lives and to make full use of their skills and abilities for the benefit of the society.<sup>248</sup> Support of governments, non-governmental organizations and families will go a long way to achieve this goal. Rashad and Khadr stress that the implications of the ageing Arab population are not limited to just the elderly, but also extend to the family. This is very much true in the Arab context where old persons are still cared, loved and respected by their family.<sup>249</sup>

### **2.2.2 Health care providers perception of elderly care versus elderly people perception**

Muslim doctors and religious scholars are often been asked by patients, other physicians and organizations as to what is Islam's opinions is on specific medical problems affecting the care and outcome of patients' disease and life. Since some of the health care issues are new, physicians have an extreme need for advice from the guiding principles of the Quran, the Sunnah and the views of the earlier and contemporary Muslim scholars.<sup>250</sup> As stated by Bella, Islamic law (Sharia) is grounded on a complete scheme of morality and, therefore, can manage to deal with the problems that occur in

medicine from a legal perspective. This scheme leaves opportunity for human rational judgment when dealing with the actualities of life. It is also sufficient to address new ethical dilemmas created by advances in science and technology.<sup>251</sup>

The first famous Muslim physician Al-Razes has expressed his disapproval of physicians who use their profession to blackmail patients or use illegal and dishonorable means. He refers to these physicians as “pseudo-doctors.” Another Muslim scholar, Ibn Kabir wrote his book, *What the Doctor Should Not Fail to Know*, where he criticized some of his contemporary “ignorant” doctors who were not committed to ethics. He suggests that any Muslim doctor who is a committed believer must know the sources of moral obligation.<sup>252</sup>

Medical thinking for more than fourteen hundred years was dominated by the writings of the preeminent second-century Greek physician and philosopher Galen of Pergamum. Muslim translations of Galen began in the eighth century; Galen’s works had been translated into Arabic and were distributed for study all over the expanding Islamic world. Consequently, Muslim medical knowledge and practice were deeply influenced, not only by Galen’s classification of diseases and therapies, but equally by his understanding of physiology, psychology, and the nature of the human body. Farage calls it the “Galeno-Islamic” tradition, after the Greek physician Galen. Studying the history of pulse diagnosis in the Galeno-Islamic medical tradition sheds light on the medical encounters between patients and physicians throughout this tradition. The use of the phrase “Galeno-Islamic” emphasizes the fact that the medical writings of all the major Muslim physicians since the ninth century, from Hunayn Ibn Ishaq and al-Razi to al-Majusi and Ibn Sina, were fundamentally indebted to the translation and transmission of

Greek medical learning and knowledge. The rise of scientific medicine around the seventeenth century marked the twilight of Galenic medicine in the West. Nevertheless, the practice of Galeno Islamic medicine still flourished as late as the mid-nineteenth century across the East and South Asia.<sup>253</sup>

Medicine was defined by Muslim physicians such as Al-Razi and Ibn Sina as the art of dealing with health, disease, and healing the sick. For a period of times, the world enriched from the improvements made by Muslim physicians in the field of health sciences. These developments were founded on the role of the Muslim physician as adopted from Islamic teachings and philosophy. Furthermore, for several years, ethics have been acknowledged as an essential requirement in becoming a physician. Although the old codes of ethics have to some extent emphasized this requirement, they were still inadequate and contained errors.<sup>254</sup> Medical ethics in Islam is part of a special branch of literature known as *adab*. *Adab* in the literature of Hadith and early after-Islamic literature means “proper manners,” “good etiquette,” “correct procedure,” and it also appears to mean ethics. There are works on the ethics of magistrates, of government, of institutions, of teachers and students; there are also works on medical ethics. These works attempt to educate good practical ethics that connected with professional ethics. Furthermore, piety is stressed in all professions. In Greek medicine, general piety and sincerity is highlighted as an attribute of a physician. As a matter of fact, this is real in all developed cultures of the ancient and unenlightened world. In ancient Egypt, Iran, and India, medicine was either a part of religion or very closely related to it. There have been two direct influences on medical ethics in Islam; the Greek and the Iranian, the former being the more textual and clearly visible.<sup>255</sup> The Hippocratic oath for physicians is found

in several works. However, the ideas of balance, the mean, and proportionality are not particularly Greek, they actually exist in the Qur'an. The work of al-Ruhavi, *Adab al-Tabib* (The Ethics of the Physician), which is one of the earliest and detailed descriptions on medical ethics, holds that it is a physician's duty to link the spiritual and bodily health; "The philosophers can only improve the soul, but the virtuous man can improve both body and soul. The physician deserves the claim that he is imitating the acts of God the Exalted as much as he can."<sup>256</sup> For Abu Bakr al-Razi, all patients should follow their physicians' orders, respect their physicians, and indeed should consider them better than their best friends. Patients should have direct contact with their physician and share with them the sensitive information concerning their health conditions. Al-Razi also has recommend physicians to be a cultured person, in order to gain patient trust and foster professional confidence. Al-Razi was acknowledged by all Muslim historians of medicine as being positively kind and merciful toward all his patients.<sup>257</sup> Thus, in Islam, ethics and spiritual medicine belong to the same ideas, and it is not possible to separate them completely, as seen in the works of al-Razi.

Farage shows that illness in this world was not the attack of a foreign entity (i.e., germ or virus), but rather the result of some form of imbalance. This imbalance could have several causes, some of which could be physical or psychological. Further, since the human being was viewed as intimately connected to the rest of the universe, sometimes described as a microcosm reflecting and relating to the macrocosm, disturbances in this relationship were seen as possible causes of sickness. In this context, the pulse was not seen as merely a beat, which could easily be measured by counting. Instead, it was seen as the core expression of the multifaceted web of different relations in which the patient

was entangled. It was “rhythmic,” “qualitative,” and “ensouled”. Therefore, the pulse had to be read and understood. Reading a pulse required a perception of the doctor-patient relationship that is entirely different from the one that is practiced today. The relationship between doctor and patient was mimetic, meaning that they mirrored one another and affected one another; physicians were using physical touch when reading the pulse as part of the routine; the doctor had to get in touch with the sick person directly, without any use of instruments. In the modern world, this intimate relationship has been transformed into a diagnostic one.<sup>258</sup>

Farage argues that this is the result of a whole shift in perception that is considered not entirely desirable. Early modern concepts of the mind-body dualism, for example, separated the self from the body, in which the body was seen as mere matter. The heart was viewed as a pump, instead of the seat of love, anger, and perception. In this concept, physicians were separated from their patients by instruments, such as the stethoscope, and the pulse lost its music. The history of the pulse then serves as a stark reminder of the changes that have taken place in the world of medicine over the past several hundred years. These changes demand that students of ethics pay close attention to historical arguments, and that we consider the contexts within which these pre-modern physicians operated. As Farage points out, contemporary Muslim medical ethics should not focus exclusively on texts from the legal tradition, but should also consider historical, medical, and philosophical texts as part of a more comprehensive discussion of ethical issues in medicine.<sup>259</sup>

Only recently, with the rise of the medical specialty of geriatrics, has medically related ethical problems of the elderly as special patient populations received attention. In

Islam, the physician must treat the patient with respect and compassion.<sup>260</sup> Many elderly persons are perfectly capable of granting or refusing consent for medical treatment, and of making life choices following their release from the hospital. Like other special populations, most notably mental patients, elderly patients who suffer from dementia lack the capacity to grant informed consent or to participate in decision-making regarding their care and treatment. In spite of these evident similarities, the elderly differ in a number of relevant respects from other patient populations. Elderly patients, as they near the end of the life span, often have a different set of values in their assessments of the quality of life compared to younger persons. Since there is no expectation that they will reenter the work force, or enjoy a return to productivity, their plight differs significantly from that of other hospitalized adults who are better able to exercise their autonomy as patients. Finally, like all residents of extended care facilities, the elderly in such settings are at risk for increased dependency and other typical consequences of institutionalization. The key concepts in bioethics include paternalism, autonomy, and informed consent, which assume special importance in the care and treatment of geriatric patients. When elderly persons suffer slight cognitive impairments, to what extent should they be permitted or encouraged to make decisions regarding their own medical care and treatment, as well as other life choices.<sup>261</sup>

There are clear practical actions that health care professionals are required to meet when caring for Muslim patients. For example, respecting patient privacy and modesty of women is held in high respect within the Islamic belief. For women in Islamic countries, when performing medical procedures, a companion should be present, and it is desirable to have a female physician in specific cases, especially for gynecological visits.<sup>262</sup> According to Nanji, it is important to note that Ibn Khaldun, the fifteenth century Muslim theorist,



argued that an ample amount of the medicine described in the Prophetic practice is traditional medicine that centers on Bedouin tradition and should be well-known from professional medicine as it was established in Muslim society.<sup>263</sup> His points are to exclude any proposition that indicates that submission to Prophetic medicine is an obligatory feature.

With respect to the Hippocratic tradition, where the interest of the physician was limited to the relationship with the patient, in the world of Islam, the fifth bioethical principle (maslaha), which is the principle of public good, has taken on a greater position. This has deeply affected the values of the medical practice today.<sup>264</sup> The roles of each member of the Muslim family continue to be traditionally diversified. In the Quran, men and woman are considered equal, but at the same time are different due to dissimilar natures. The prime job of the man is to support the family economically, where as the primary responsibility of the woman is to raise the children. The man generally makes decisions for elderly members in the family, whilst the woman bears above all the burden of care.<sup>265</sup>

In many Islamic countries (e.g. Egypt, Pakistan, and Turkey), the wishes of elderly patients are regularly subsidiary to the families and/or of the social group to which the patient belongs. Also elderly patients with little education expect the doctors to take decisions for the good of the patients and fear if they behave otherwise, they would be offending the doctors. These situations are translated into a reduced autonomy of the patients.<sup>266</sup> However, in Western countries, the respect for patient autonomy formulates the primary element of bioethics; the patient is treated as a rational and independent individual. Inversely, in the majority of the world's population, the family (or other intermediate social groups such as clans, etc.) plays often a significant part in the decision-making process on the health of the elderly individuals, mainly for the purpose of avoiding any psychological

suffering of the patient. In traditional settings, a strong internal structure and social bonds connect the individual members within the family. In Muslim contexts, patients typically worship the physician and believe them to be godlike. In other words, individual identity takes a lesser priority with respect to the family identity.<sup>267</sup> Thus, the decision can easily be given to the most authoritative figure in the context in which it is taken (e.g. father figure or physician).<sup>268</sup>

When the individual in the decision-making role of the family is strong, the interests and wishes of the elderly people often become weak and in some cases may be ignored. Also, in very poor and/or disadvantaged situations, the survival of the vulnerable individuals may be dependent on economic burdens, where treatment maybe withheld if the cost is expensive. Medical technologies tend to reduce the familiar relationships between the families and the patient, through exchanging these relationships with a contractual model similar to the one that direct the Western countries.<sup>269</sup> Elderly patient who are ill infrequently make autonomous decisions regarding their care. It is usually the family that chooses who to consult for treatment and which procedures or treatments to take. The families in Islamic countries also play a role of facilitation between the patient and the physician. However, it often still seems challenging for physicians to undertake an open discussion with the patients regarding the decision-making responsibilities of their guardians. Specifically, because of the authority given to physicians in Islamic countries, physicians must make an effort to involve the weakest members in the decision-making process, even at the cost of resisting the governing cultural customs.<sup>270</sup>

Additionally, the physician should provide complete information to the elderly patient or their guardian on the diagnosis or treatment that he plans. In fact, it seemed that in

the 1985, it was a common practice among physicians in the Islamic countries to not give female patients any right to consent for treatment if it was deemed necessary.<sup>271</sup> Cases like this still exist; however, these days' physicians communicate with the guardian of the patient (generally the husband, son or a brother) to get consent for the treatment. Absence of communication and changing information between health care providers and the elderly patient or families is one of the primary reasons that lead to legal dispute.<sup>272</sup>

The Muslim physician shares with the Muslim patient the faith in God and destiny, and the belief that there is a cure for every illness. But the physician must have something more to know such as the proper diagnosis and the proper treatment. Physician must be aware of the task appointed to him as the agent of healing. By being an agent, he believes that the act of healing is not entirely his, but it depends on God's will. The Prophet said: "For each disease there is a cure: and when the (right) treatment is given, the disease is cured by the Will of Allah." The art of healing, which is called the medical profession in modern language, has been highly respected all through centuries. The scheme here is that a physician's diagnosis included the spiritual, psychological and social sides of the patient over and above the pathological aspects. In health care practice, the Muslim physicians find themselves obliged by strict professional ethics plus Islamic directives delivered from his belief. Muslim physicians, who follow Islamic teachings all through, are expected to behave differently on some occasions and to meet greater responsibilities compared to other non-Muslim physicians.<sup>273</sup>

By accepting the fact that God is the curer and that the physician is only an agent, both patients and their physicians fight the diseases with less suffering and worry. According to Athar, it is the spiritual belief that improves the psychological status of the

patient and enhances his morale, thus help him to overcome his physical weakness and illness. Therefore, Muslim physicians must make their faith the strength of their profession. Muslim physician should not be guided in such issues merely by the law of the country, but they must also find the Islamic answer and adopt it.<sup>274</sup>

It may be worthwhile to note that during the recent years, and due to a variety of reasons, a narrow approach or lack of emphasis on ethics in medical training was visible. As a result the physician is no longer seen as a defender of ethics and morality. The definition of ethics and morality in medicine has lately become a favorite topic for politicians and non-physician who lack the insight into the importance of patient-physician relationship. Therefore, it is the time that the physician takes this ground, since he is still regarded very highly and trusted by the people.<sup>275</sup>

### **2.3 Conclusion**

This chapter has explored trends in ageing care in Islamic societies in the context of significant recent changes in procreation and family formation and composition. Improvements in life expectancy have accelerated ageing of the population in many countries including the Arab countries. This chapter also reviewed Muslim way of respecting elderly persons. Islamic teachings stress the importance of respecting elders, particular parents. The discussions above highlighted Islam attitudes towards elderly health and care. Followed by history of the health care professionals duties in Islam and the medical practice transformation and manners towards elderly health care.

One of the conclusions of this chapter is that religion is important to many individuals' beliefs and values, and can be the angel that provides individuals wellbeing in

times of sickness and dying. Religion works as the support that gives people strength during extremely difficult times. Its approaches to bioethics begin with the belief that there is a greater power, and a set of religious texts, that govern the parameters for human action.<sup>276</sup> Islam exists within cultures with a remarkable history. Throughout history, the arguments and the determination of moral conflicts have altered due to the period, place, belief and the cultural practice of a society.<sup>277</sup> The argument is that there is a need to distinguish and recognize those features used earlier years, which attribute treatment and curing by how they were accepted within the Quran, towards the intellectual and cultural adjustment of beliefs and practices that were not straightforwardly originated from the Quran, Sunnah or Islamic tradition. Healing is one of the analogies used in the Quran to explain its function for civilization.

Biomedical ethics in Islam regulates the use of old Islamic values, philosophies of moral reasoning, juridical-ethical principles, and scholarly perspectives to address a variety of contemporary healthcare dilemmas. Modifications in medicine mandate further examination and discussion towards building greater consciousness of the new concerns through an Islamic ethics system, which is appropriate for communication with other religious and non-religious organizations. In Muslim bioethics, the four principles of ethics still find balance with the general principles of Muslim law. An important difference exists in the principle of respect for autonomy, where the priority in the Muslim context is given to the public benefit. In contrast, individual needs are prioritized in Western society.<sup>278</sup> As mentioned above in this chapter, the experience of aging bodies is complex and influenced by structural and cultural forces and the myriad interactions that occur in the overlapping and discrete contexts in which we live.

The process of aging is not considered to be entirely free from cultural judgments concerning their bodies. Individuals are recognized as social beings, where the body is partly a physical phenomenon and partly a social construct. Given the importance of images and other cultural ideals as ingredients in shaping and evaluating one's identity, we see these ideals as potentially damaging to those who cannot live up to them or who do not wish to do so. If we do not see ourselves in these master narratives, our ability to interact with the larger community may be constrained along with our freedom to act as we might wish. As our bodies become more uncertain, our need for what is familiar and identity confirming is greater. Islam, however, is more than a religion and has more than a spiritual value in Muslims' lives. Islam is, above all, a social order; in which faith is reflection of the way a believer follows Islamic codes of conduct.

Family relations, including the rights and responsibilities of old-age care, have largely benefited from the Holy Quran's commandments. Respectful behavior and devoted service to parents is a must in Islam. Worship of Allah is always a necessity; similarly service to parents is always necessary throughout their lifetimes. Teachings prescribed in the Quran are introduced with regard to good behavior towards parents. For example, giving your mother gratitude and respect, serving parents in old age with kindness, and paying respect for all elderly persons are encouraged by the Quran. All religions teach that children must respect and care for their elders. Recognizing and practicing respect and care for parent and elders is taken even more emphatically in Islamic teaching.<sup>279</sup>

Furthermore, in many Muslim countries, however, women still struggle with inequality and restrictive access to health care. In fact, many of the oppressive practices

do not originate from Islam itself, but are rather part of local cultural traditions integrated at some time into the religious rules of Muslim governments.<sup>280</sup> Although the state and circumstances of older individuals and the chances offered to them differ from one Arab country to another, in general, older people in the region face certain common vulnerabilities that have special effects on their care. Most particularly, the health care, cultural, and social challenges brought about by modernity compromise family cohesion and threaten old-age dignity and respect for autonomy. Human dignity does exist in the Islamic religion and the declaration of the Quran, however, the application and the functions of the concept in elderly health care are disregarded, due to the cultural understanding and interpretations of the concept. Health care providers and societies in Islamic countries have, thus, missed the momentum of implementing a strong old-age health and social support system that can maintain their dignity and respect for autonomy and thus, meet the needs of their older persons. To remedy this problem, Arab countries need to invest in building and empowering bioethical education. The following chapter will study the history of the ethical notions of dignity, its function and meaning throughout Western history. The discussion will then move to the principle of respect for autonomy in health care, and the difficulty in applying both concepts in a health care practice.

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## **Chapter 3: History of the ethical notions of dignity and respect for autonomy in health care and the difficulty in applying both concepts in health care practice**

### **3.1 Introduction**

The concept of respect for self-government has been deeply rooted in American culture. Medical ethics came about during a time of societal flux, and became a key subject during the birth of the United States as the fundamental idea of individual's rights.<sup>281</sup> Since the late 1960s, autonomy has been at the core of medical ethics. It has been built upon and changed by multiple cultural forces, combining in the effort to defend individuality and self-determined choices. It became an extrapolation from case law to rights of patients, which was practiced under the philosophical umbrellas of autonomy. Thus, autonomy has a uniquely complicated history; having been developed in the modern-day idea of self-governance, and it acquired its most determined philosophical explanation in Kant's moral philosophy. According to Tauber, Kant's discussion of autonomy is different from today's understanding and use of the concept. However, the Kantian position is beneficial in highlighting that self-governance is not equal to autonomy, and this dissimilarity outlines the limits of autonomy in the medical setting.<sup>282</sup>

The works of Cicero, a Roman philosopher, is an important starting point for the roots of the way the concept of "dignity" is used in our culture today. In his writings, the concept of dignity is presented in two distinct manners.<sup>283</sup> The first one is social and refers to the public recognition of individual's social position. As public recognition, dignity is dependent on the reaction of a group of people. Since it depends on a collective, there is not one specific subject or a clearly defined group of subjects that can



be held responsible for acknowledging or refusing this public recognition. However, dignity as public recognition is not stable or permanent. The social position may be more or less connected with power, but the recognition of this position is dependent upon the outlook of others.<sup>284</sup> This means that the concept of dignity is used in order to sustain a certain social order.

Cicero uses the concept of dignity in another way as well: as the intrinsic and characteristic quality by which human beings are distinct from other beings. According to the philosophy of the Stoa, this intrinsic and characteristic quality is reason (ratio) and the fact that human beings are endowed with reason distinguishes them from other living beings such as plants and animals.<sup>285</sup> Thus, in this second meaning, the concept of dignity has a much different function. It is used in order to distinguish human beings from other entities that surround them. This distinction is based upon a certain concept of rationality and a valuation of this concept. Rationality is seen as a trait possessed by human beings exclusively, and it is considered to be intrinsic since it defines the species as such (animal rationale). At first sight, this notion of intrinsic dignity may seem to be a very concrete and permanent evaluation. At a second glance, however, the notion of intrinsic dignity does not refer to a practice, but rather to an idea. The stability of this idea is as strong as the authority or acceptability of the philosophy that suggests this view. As a matter of fact, in history and up to this day, many philosophers, theologians and institutions have proposed and sustained the idea of intrinsic dignity.<sup>286</sup>

As a matter of fact, the idea of intrinsic dignity had been taken up in various ways outside or apart from the Christian tradition, and more than six months long before the Universal Declaration of Human Rights in 1948.<sup>287</sup> The Renaissance philosopher Pica

della Mirandola (1463–1493) in his *Oratio de Homine Dignitate* made an important step by breaking free from the Christian theological foundation of dignity as he proclaimed the freedom of man as his dignity.<sup>288,289</sup> After the Renaissance thought had put man at the center of the universe, and the concept of dignity would evolve further in different directions. With this in mind, philosophers like Hobbes defines dignity as simply “the public worth of a man, which is the value set on him by the common wealth.” According to this notion, dignity can be compared with one’s price on the market, and not an absolute value but “a thing dependent on the need and judgment of another.”<sup>290</sup>

In the contemporary world, Kant was one of the earlier thinkers to set both concepts of respect and dignity at the heart of moral philosophy. From the 18th century Kant defines human dignity as a worth that has no price. In his *Grounding for the Metaphysics of Morals* he contends that some objects can be exchanged for a price or can be bartered for their value, but some objects are above value and cannot be exchanged or traded.<sup>291</sup> For example, the law must prohibit the disadvantaged people from being persuaded to exchange their organs for money to help themselves or their families.<sup>292</sup> Thus, he intends to explain that human beings are individuals and not something that can be used as a means of trade. In Kant’s philosophy the idea of intrinsic worth is directly related to the foundations of morality. He claims that individuals should always be treated with respect toward their dignity, and always as ends in themselves. After all, they can be treated as a means and an end at the same time, but never only as a means.<sup>293</sup> Even though, the variation of the old idea of intrinsic dignity is no longer dependent on a Christian worldview, it still depends on the authority of an idea, or a certain method of thinking. In that sense Kant’s rational foundation of his ethical thinking, influential as it

is, is not different from that of Cicero. Consequently, dignity refers to an idea that is not based on a practice, but on other ideas about reality and the way we should live in it.<sup>294</sup>

Both of these ideas share that having a dignity involves having a set of rights. In the event of basic dignity, this set of rights is human rights, the rights, which the United Nations and others have defined. As can be seen, the dignity of merit was the prominent notion in the Roman empire and which is still flourishing in our ordinary discourse, while the second is the dignity attached to the property of being human, which is the philosophical notion developed since the Renaissance. According to Nordenfelt, the dignity of merit is easy to exemplify. For example, a person who has been appointed to a top position has received a dignity, meaning an honor for his or her achievement. One thing evident with regard to the dignity of merit is that different people have different respective degrees of dignity. They are on different levels on their dignity scales. Thus, one and the same person can be placed on several scales of dignity.<sup>295</sup> However, the word has an important sphere about it that is not suitable with regard to all the kinds of scales. Yet, by stretching the use of ordinary language a bit the word could have a variety of uses for these descriptive notions.

Nordenfelt assumes that there is a great variety of species when considering the dignity of merit that exists. The various kinds of dignity of merit call for respect at different levels. The respect involves paying attention to the rights possessed by the person with dignity. The second type of dignity is the one that we all as humans have; been born with as humans, or are expected to have solely because we are humans. It is precisely human value, and we are all assumed to have this intrinsically at the same level.<sup>296</sup> Thus, with respect to this type of unearned dignity, all people are alike. This

outlook teaches primarily that all people have the same human rights. These rights are the same that the United Nations has approved in its Declaration on Human rights of 1948, stating in the first article: “All human beings are born free, equal in dignity and human rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.”<sup>297</sup>

For this reasons, every elderly person has his or her intrinsic value, which involves a number of rights, such as the rights of the UN declaration. The elderly individual is not excluded from any of these rights because he/she has reached a specific later stage in life. There is however, a different element to be observed in the fact that a few of the rights do not pertain to the elderly due to their age. For example, the right to work, or the right to proper school education, which are deemed irrelevant. Other fundamental rights, on the contrary, have better application to the elderly; specifically, the universal right to receive proper medical care in the event of sickness or disability. In the final analysis, this value of intrinsic dignity is worth restating, since it is so often violated in practice and in institutions for the elderly. A reason for this may be the somewhat lower public position into which the elderly have been sequestered within many circles, especially among the younger generation.<sup>298</sup>

Previously in chapter 2, the discussion touched on the growing concern about the ways in which the notion of dignity and respect for autonomy is viewed in Islamic countries, both generally and within the arena of aging. Therefore, in order to expand the understanding of ethics and aging, this chapter explores the meaning and functions of the notion of dignity and respect for autonomy in Western culture. This chapter is structured as follows. First there will be a short impression of the history of the concept of dignity

and respect for autonomy in order to show how both concepts have been applied to the practice of health care. Subsequently, both concepts will be introduced according to their development and use in Western culture, in order to examine their functions in relation to the health care that has to be provided. This takes into the account the role that healthcare workers can have in dignified care. Therefore, the following section aims to further clarify the meaning of dignity, and how it should be operated with the health care of older people. This part will be followed by a discourse on the ethical dilemmas associated with elderly care.

### **3.2. Human dignity functions and meaning throughout Western history**

The term dignity originates from the Latin words “dignus” and “dignitas,” which means both worthy and worth respectively.<sup>299</sup> According to Jacelon, individual integrity is a vigorous inherent value of a person’s health, autonomy and dignity.<sup>300</sup> Today, the concept of dignity has developed wide acceptance, yet its status and description as a philosophical concept are hotly debated. This debate is enhanced by the political importance the idea has achieved, especially in the United States and in international bioethics at organizations such as UNESCO, the European Commission, and the Council of Europe. There has been a critical increase in concern over notions of dignity in modern times as a result of complex relationships being built between technology and humans. A second problem with dignity lies in the fact that it accommodates itself toward undesirable distinctions between one person and another.<sup>301</sup>

According to Andorno the principle of respect for human dignity has an essential role in bioethics, especially in the UNESCO Universal Declaration on Bioethics and

Human Rights. This legal and ethical tool is seen as an addition to the field of international human rights law, into the bioethics field. The necessity for dignity functions as an actual alarm for the necessity to establish respect among the inherent value of human beings and for the integrity of the human condition. However, dignity alone cannot resolve most of the problems presented by ethical concern in biomedical practice. This is the reason that international biolaw integrates the appeal to human dignity as a main principle with the appeal to human rights, which delivers an efficient and practical approach for handling the bioethical issues globally.<sup>302</sup>

Some people believe that that idea of human dignity that has developed from the religious texts is innately changeable; it serves as a veil for religious doctrines that have no reasonable room in ordinary bioethics. Macklin, who supports eliminating the phrase “dignity” utterly from bioethics, believes that religious sources of human dignity justify why so many publications refer to human dignity, as if it means something beyond respect for an individual’s autonomy.<sup>303</sup> Furthermore, those who would reject all religious justifications for its applications in human dignity issues have the responsibility of showing what it is about human beings that necessitates us to treat them with respect. Why can men rightfully uphold their life, liberty, and pursuit of happiness, if it was not because a God granted them certain basic rights?<sup>304</sup>

Supporting patient dignity in health care requires recognizing the patient’s beliefs and expectations, and assuring that it is allied with dignity, as long as it is also thoughtful to other patients’ rights and healthcare resources. This goes along with Seedhouse’s observation that dignity is about corresponding individual’s needs with his or her situations.<sup>305</sup> Seedhouse focuses on personal autonomy in relation to dignity, as he

defines it as matching one's capabilities to circumstances. He argues that if health care providers want to endorse a person's dignity, then they must make dignity a subjective experience rather than a moral quality subject to the ruling of others.<sup>306</sup> This qualification centers on whether an individual feels dignified or undignified. Haddock determines dignity as the capability to feel respected in relation to others.<sup>307</sup> Matiti adds that the knowledge necessary to preserve an individual's dignity is acquired through socialization, and is developed as a result of how the individuals are nurtured.<sup>308</sup>

The regular use of the word dignity in national constitutions and international declarations endorsed in the outcome of World War II is another noticeable source for human dignity dialogues. Therefore, by declaring a certainty in human dignity these instruments would seem to point beyond the umbrella of protection toward rights supported in the American beginning in relation to life, liberty, and the pursuit of happiness and other modern natural right theories. In the *Universal Declaration of Human Rights* (1948), acknowledgment of the intrinsic dignity and of the equivalent and absolute rights of all human beings is believed to be the base of liberty, justice, and peace in the world. At least 37 national constitutions approved since 1945 refer clearly to human dignity, including the *Basic Law (Grundgesetz) of Germany* (1949), which begins "Human dignity is inviolable. To respect and protect it is the duty of all state authority."<sup>309,310</sup>

After all, the principle of respect for human dignity embraces an outstanding status in the international activities dealing with bioethics that have been adopted during the last decade. The focus on human dignity is important enough to lead researchers to describe this concept as "the shaping principle" of international bioethics. The increased

attention directed toward this notion in bioethics is seen as a right move in matter that needs to be cautiously measured.<sup>311</sup> Thus, it is not unexpected that the 2005 Universal Declaration on Bioethics and Human Rights, which articulates a set of norms to mentor biomedical practice, gives the greatest attention to the principle of respect for “human dignity, human rights and fundamental freedoms.” The Universal Declaration of Human Rights of 1948 states in its Preamble that “the inherent dignity” of all members of the human family is “the foundation of freedom, justice and peace in the world.”<sup>312</sup>

Afterward, the notion of human dignity has been at the core of the major human rights activities, starting with the two international treaties on human rights adopted in 1966: the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICECSR), as well as in most treaties prohibiting torture, slavery, inhuman and demeaning actions and injustice. Although the concept of human dignity has always held an important role in international law, the key role it plays in the newly emerging international biomedical law is certainly remarkable. It was also described as the “overarching principle” of international biolaw.<sup>313</sup> Regarding the 2005 UNESCO Declaration, respect for human dignity is not only positioned first in the list of principles that should rule the biomedical field, but it also embodies the central aim of the whole instrument.

It is also important to consider that the examination of international human rights instruments and of the decisions of national and international courts shows indeed that human dignity have several roles and multiple functions at different positions. First of all, dignity provides the innermost justification for human rights. It is also stated as the supporting reason behind the abolishing of intolerant practices, along with torture,



humiliating treatment, and various forms of improper exploitation of humans. In this regard, the UNESCO Universal Declaration on Bioethics and Human Rights is a great example of the several roles that human dignity can play. As stated above, the enhancement of respect for human dignity represents the core goal of the document, and it is the first principle that should administer the biomedical issues. This principle is notably the basis for the prevention of discrimination of individuals or groups, the framework within which cultural diversity is to be respected, and the informative principle for a proper understanding of all the Declaration's provisions.<sup>314</sup>

The issue that mattered most after 1945 was not attaining agreement of human dignity but rather ensuring, as a practical matter, that the most unethical behavior imposed on large populations during the war would never be repeated in the future. Nevertheless, if human dignity is regarded as nothing more than an indefinite factor in virtue of which people are obliged to treat all others with respect, then some bioethicists have questioned why has it been implored at all.<sup>315</sup> Annas, Andrews, et al., claim that the concept of human dignity begins to enter a realm of understanding as the last barrier against the modification of some basic features of the human species that might result from practices such as reproductive cloning interventions. However, it should be noted that simple acknowledgement of human rights is inadequate to handle these new challenges, because human rights only belong to existing individuals, not to humanity as a whole. Indeed, an act like reproductive cloning, which is done prior to the existence of an individual, technically would not violate the rights and dignity of that yet unborn individual. This is realized in the sense that they may or not come into existence, and not a person, neither from a legal nor from a theoretical viewpoint.<sup>316</sup>

This is the reason that the 1997 Universal Declaration on the Human Genome and Human Rights directly appeals to the notion of human dignity, not to human rights, in order to deny both practices. In fact, biomedical practice is thoroughly connected to the most basic human rights, explicitly the rights to life, to physical integrity, to privacy, and to access to basic health care. Therefore, if human dignity is acknowledged as the groundwork on which human rights are based, then there is no doubt that it is appealed as the absolute rationale of the legal standards leading the biomedical practice.<sup>317</sup> It is not surprising that the concept of dignity is closely related to the concept of respect for autonomy. However, Andorno claims that it would be wrong to believe that we can prevent the difficulties presented by the intellectual notion of dignity just by substituting it with the more understandable idea of respect for autonomy. Furthermore, Andorno declares that this would produce a flawed solution because respect for autonomy is just the result of human dignity, not dignity itself. In the same way a bell's sound is a result formed by the bell, not the bell itself. In fact, the idea of dignity is not a substitute for respect; dignity is what provides the basis and reasoning to develop respect for individuals.<sup>318</sup>

Moreover, Macklin argues that respect for persons is an adequate principle for bioethics, and one that involves the need to acquire voluntary, informed consent, the requirement to protect confidentiality, and the need to avoid discrimination and abusive practices.<sup>319</sup> In addition, Pullman recites that autonomy is important to secure aspects of dignity, but should not be confounded with the whole of it.<sup>320</sup> Pullman's view of an ethic of dignity does not deny the importance of autonomy as a value, but he stresses on its limitations, and suggests the importance of dignity. This is especially true where

autonomy is lacking. Adding to that, Howard declares that the meaning of human dignity as a matter of fact is a cultural understanding of what it means to be human, along with the way in which one can have a dignified life with other human beings.<sup>321</sup> Thus, this definition supports the presence of a variety of commonplace cultural understandings of human dignity and, hence, there is more than one true meaning of human dignity, and by so to fit the cultural heterogeneous reality.<sup>322</sup> The maintenance of one's dignity in health care depends on the context of care that is presented during health care providers interactions with the patient, as each of them represents a chance to show respect. For example, beds and baths to patients, and giving medications challenges the health care providers to consider what information should be shared and how necessarily insensitive events are managed to minimize the loss of privacy.<sup>323</sup>

### **3.3. Respect for autonomy functions and meaning throughout Western history**

The importance of autonomy is widely regarded as the most important ethical concept in American culture.<sup>324</sup> The word autonomy means self-rule.<sup>325</sup> In bioethics, the concept of autonomy is relatively new. In the 1960s, medical ethics was labeled, “internal to medicine those values, norms, and rules intrinsic to the actual practice of health care.”<sup>326</sup> In the 20th century, many customary features of authority were examined, as showed in the civil rights, anti-war, and feminist activities; all have then moved the practice of medicine as well. The debates on medical ethics that formerly had been adhered to within the sphere offered a fresh and advanced approach of thinking in which the ethical principles of society, including the rights of the individual, were applied to the medical practice. In health care practice, the principle of respect for autonomy entails

respect for the decision-making capacity of competent adults, and nowadays the principle is totally involved in medical practice. The patient's right to grant or deny medical care has changed the scheme of authority in the doctor-patient relationship, and has engaged the patient more in his or her own care plans. Mutual decision-making has become the custom; it is regarded as necessary for respecting the individual autonomy and his or her dignity.<sup>327</sup>

According to Schneider, it is simpler to apply and protect the principle of respect for autonomy in the case of a well-informed adult of sound mind.<sup>328</sup> But when the concept is challenged with patients whose competency (legal status) may be in question due to a cognitive impairment, or mentally ill, then the principle is sometimes interrupted or reduced for such patients; but rarely it is placed away in favor of another ethical principle like beneficence, non-maleficence, or justice. Advance directives are one of the most recognizable tools for extending autonomy. A living will permits an individual who is competent to be autonomous and select the care he will receive when he is incapable to make decisions. Also autonomy extends by allowing others to act on patients' behalf when a patient is unable to. This can be made legally, through a durable power of attorney, or informally through assigning family and others to act as patients' proxy. Also, in ethical standings, a substituted judgment entails certain information about the individual, and his or her values and desires.<sup>329</sup>

Respect for autonomy as a primary ethical principle, is comprehensive in its meaning and can refer to individuals, their will, or an activity in society. Self-control is viewed as an essential part of autonomy and can be described as the capability of an individual to bring about norms of behavior and a course of action.<sup>330</sup> This means that the

person has the liberty to choose his or her own actions according to his or her own ideas. However, in reality, people do have different levels of autonomy. According to Veatch and Fry, the context is usually gray, with no one being either entirely autonomous or entirely dependent,<sup>331</sup> and this difficulty increases the complicatedness of health care involvements. To further clarify autonomy, Mappes and Zembaty deliberate three functions of autonomy. The first function is the freedom of intentional and voluntary action. The second function is the liberty of choice, which describes how the person identifies a selected choice of action. The third function is the effective discussion and it emphasizes on the internal aspects. The individual must be able to think reasonably and be able to act according to his or her own plan of action without coercion.<sup>332</sup> Wilson and Netting characterize society's paternalistic attitude towards the elderly as interrupting with the second function, through letting health care providers to decide on patient behalf what is best for him or her.<sup>333</sup>

In fact, the idea that patients have moral rights to choose their own medical treatment and to be well-informed about their diagnosis and condition to make medical decisions was a significant challenge of the bioethics movement to conventional medicine, and still a challenge in some countries.<sup>334</sup> In the United States and elsewhere, this idea has shifted the physician-patient relationship. According to Gold for example, in 1961, 88 percent of physicians would not disclose the diagnosis to patients with cancer; today however, the majority of American physicians feel obliged to reveal that information to the patients.<sup>335</sup>

In recent times, there has been a reconsideration of the meaning and values of patient autonomy. According to Baumgarten, some are implying that the attention on

autonomy is a uniquely American aspect, which is an assumption of their cultural diversities and interest with individualism. Previously, in the United States, the focus on autonomy developed due to the increasing power in general, especially man power, and it was a time for people who had not back then been in the mainstream of the medical profession; in specific, women, Hispanics, African Americans, and other minorities to be heard.<sup>336</sup> These evolutions supported an American movement to address and challenge physicians' paternalistic attitudes in health care. Therefore, respecting patient autonomy is a lot more than just a distinctive American or Western cultural way.

According to Baumgarten, the ethical influence of patient autonomy is based on the nature of medical decisions and on respect for the dignity of individuals. The position of non-medical values is even more recognizable for a patient who has religious concerns to some medical care and procedures; for example some Muslim women consider treatment by male physicians to be forbidden due to her religious beliefs.<sup>337</sup> Furthermore, Baumgarten declares that the idea that a patient's ethical values should be respected in regards to medical treatment and not the physician's ethical values who is in control, was attained due to the bioethics movement and its support of patient autonomy.<sup>338</sup> Although Dworkin implies that, it is likely possible to define a useful concept of autonomy that there is no single conception of autonomy, but that we have one concept and many. Furthermore, Dworkin provides several ways in which autonomy has been utilized; which include autonomy as freedom to act, as dignity, as liberty of the will, as independence, and as critical reflection. Also as self-control, choosing freely one's own moral position and accepting responsibility for their own choices.<sup>339</sup> In summary, autonomy (literally, self rule) is the ability to freely and independently choose and

exercise the chosen care. In health care practice, respecting the individual's autonomy has many at first sight implications; moreover, it necessitates health care professionals to consult patients and obtain their fully informed agreement before doing any health care to them.

In addition, many fundamental reasons contribute to respecting patient autonomy. Patients who are fully informed about their diagnosis and the treatment are more likely to follow physicians' recommendations and treatments. Even when a physician has to communicate the unfriendly news of diagnosis, indeed, telling the truth to patients provides them an opportunity to put their matters of life as a whole in order. Additionally, if doctors start a practice of withholding bad information from patients, then patients will be less likely to trust the assurance of doctors when the information is not bad. Nevertheless, many disapprove the stress on patient autonomy and advocate that a physician's main responsibility is to do what is the best interest of his patients, and such revealing of information and letting patients to select an important medical care decision would lead to inappropriate choices in some cases.<sup>340</sup>

In like manner, autonomy antagonists contend that physicians need to make medical decisions for their patient, because many competent patients would still choose inappropriate and unwisely choices. For instance, a patient may reject what a physician sees to be useful treatment, even after being informed of the possibility of harmful side effects of treatment. Regardless, the issue with this opposition is that it gives no reason for treating persons as needing protection from their irrational choices, and yet believes they are allowed to make free choices for their own lives outside the health care domain. It is basic to the dignity of human beings that they be given the right to make choices

about their own lives.<sup>341</sup> In every day's life, people are facing an important decision as those of patients; the choice of a marriage, the choice of a career, the ongoing choice of what is importance to give to the pursuit of challenging ethical, worldly, and spiritual needs, even the potentially life and death choice of whether to consult a physician in general. Part of human nature is making error; even competent individuals sometimes miss to choose the best available choices in all of these areas. However, believing that it is a matter of human dignity to respect the autonomy of people and their liberty to make their own decisions in different areas where mainly their own health is at danger, then the burden of evidence is on those who would still reject people freedom when they become hospitalized.<sup>342</sup>

In brief, respect is something that we give others; it means consideration for them and their needs as individuals. Therefore, showing respect should be manifested in every interaction; it is about being polite and gentle during physical contact, giving appropriate information, and ensuring that people are not frightened to ring the bell.<sup>343</sup> Furthermore, respect means that people are not treated as objects and they are not spoken over, or about, as if they were invisible. They are acknowledged as people with a life history that existed before they came to hospital.<sup>344</sup> Moreover, with the demographic movements, health care providers will be caring for an increasing number of elderly people with challenging health problems, and these problems in turn may lead to ethical dilemmas. Therefore, health care providers should be well acquainted with the ethical dilemmas that are frequently faced when caring for elderly patients. Some of these dilemmas will be included in the following discussion, such as safeguarding informed consent and privacy,



decision-making capacity and decision-making process, and fostering advance care planning.

### **3.3.1. Privacy and confidentiality**

Factors associated with families and professionals shape the exercise of autonomy in caring for older persons at home. For families, the factors include available caregiving resources, personal relations, and intergenerational issues. For professionals, they include home care reimbursement, worker availability, and public policy regulation.<sup>345</sup> Resource shortages or diminished capacity for relations for both families and professionals may serve to curtail autonomy. The dilemmas families and professionals face in preserving the autonomy of older persons are widely acknowledged.<sup>346</sup> In fact, threats to autonomy are not uncommon in the lives of older persons. Sometimes the threats are subtle, as when family members exaggerate information, or professionals use knowledge or technology to gain authority.<sup>347</sup> Other times the threats are obvious, as when families or professionals simply substitute their own values or goals for those of the older person.<sup>348</sup>

Confidentiality is an issue with the older population, as a combination of bio-psycho-social aspects requires input from numerous professionals. Medical confidentiality is an indication of respecting the individual's autonomy. Health care providers directly or indirectly promise their patients that they will keep their information confidential, thus, keeping promises is a way of respecting the individual's autonomy. In fact, a way of operating our own life is depended on being able to trust others.<sup>349</sup> Therefore, without such assurance of confidentiality, patients are less likely to reveal the highly private and sensitive information that is needed for their ideal care; accordingly,

maintaining confidentiality not only respects patients' autonomy but also increases the possibility of being able to help them.

The care of elderly people will always require consideration in each particular setting, but, if the moral assumption is that the caring responsibility is a right to respect patient wishes, then the key aspect will be respect. To be able to show this respect, health care providers must have knowledge and show honesty. When this is achieved, then there is no conflict between meeting elderly people' needs and respecting their own privacy.<sup>350</sup> That is to say that the maintenance of privacy allows for a feeling of personal control, self-evaluation, and release from societal expectations and the situational context for sharing information.<sup>351</sup> It has been suggested that the loss of privacy is major when elderly people become dependent.<sup>352</sup> In nursing homes and long-term care institutions for instance, it appears that nurses know what is best for their customers, but it is not always possible to give attention to people needs due to the shortage of time and resources.<sup>353</sup>

Furthermore, for an individual's well being, medical privacy is crucially important.<sup>354</sup> Despite this importance of privacy of elderly persons, there is very little research into the concept of privacy in institutional care. Privacy stresses the individuality of human beings and one's private life. It concerns an individual's decision to deny or grant access to one's personal zone, one's private home, individual behaviors and attitudes, and social networks.<sup>355</sup> Therefore, in order to understand individual views of privacy there should be a consideration to the individual's social, physical, and emotional magnitudes.<sup>356</sup> The physical aspect of privacy is considered to be related to the concepts of personal space as a requirement for privacy. In fact, personal space explains an area and a protection zone that separates one person from another. It combines the physical

space and the behavior of human beings that gives people the opportunity to be alone. Therefore, the violation of personal space increases an individual's concern level and can elicit aggressive behavior. For instance, it has been stated that in nursing home some of the elderly women who had professional career in the past are reacting with greater nervousness when their zone is invaded.<sup>357</sup> Thus, social privacy comprises an individual's ability to control social relations. On the other hand, residents who are alone in their room have no privacy if they have no opportunity to socialize with others in ways that determine their identity from others. Applegate and Morse indicate that the conception of the home as a private place is important when considering physical privacy, person's identity, and self-esteem. Therefore, it is clear that moving individuals from their own home to a residential home can be seen as a threat to identity and personal control.<sup>358</sup>

In health care practice, the laws and other regulations protect the confidentiality and disclosure of individual information. In addition, ensuring individuals' right to privacy have increased due to the advances in modern technology. Applegate argues that residents' privacy is not respected in some hospital or institutions; as personal information was not preserved privately.<sup>359</sup> In fact, the experience of what considers as loss of privacy affects an individual's feeling of loss, and it is different across cultures. Also, the meaning and use of personal space is subject to cultural variation. Therefore, expectations with regard to cultural patterns for respecting the privacy of others may also be overlooked and accepted in different settings.<sup>360</sup>

The ethical principle of respect for autonomy obliges health care professionals to preserve patient confidentiality. Preserving confidentiality is required for the appropriate assessment and cure of patients. In order to appropriately evaluates and treats the

patient's, physician must be able to ask and gain information about possibly sensitive subjects, for example; history of mental illness, or substance abuse. In that event, the patient must be confident that the physician will not disclose the patient's information to others.<sup>361</sup> In spite of that, legal obligations may necessitate physicians to disclose information in order to provide the best interests of community. For example, laws for suspected abuse of elderly persons.<sup>362</sup> In this situation, the obligation to protect the patient and others from abusing behavior overrules the obligation to maintain confidentiality.<sup>363</sup>

Finally, ethics is concerned with how we ought to act towards one another; and what is right and wrong to do to another individual; basically, ethics has to do with a view of life and human nature. However, these issues are often associated with dramatic decisions such as life and death, or as a consequence medical technology and research. Elderly people encounter a type of everyday ethics in their daily life, concerning the various aspects of care. These everyday events are not subject to analysis each time they are made. Rather, they suggest, intentionally or unintentionally the fundamental attitudes of health care providers.<sup>364</sup> Within health care practice, the familiar ethical principles for respect for autonomy are direct evidence of our common belief that certain freedoms and rights exist for all. This view, transferred to the realities of health care, thus to care for another human being is a trust one is given, not a right that one has. To care is therefore a responsibility that can only be received, and never detained. In the health care professions, the importance of the ethical responsibility is evident in the inequalities that exist between health care providers and patients. The basis of caring is thus to aid the human being who, as a patient, is in a vulnerable position but who still has rights to

privacy, and a sick person is only dependent because of his or her weakness. Also attitudes and behavior to express love, affection and gratitude is itself a respect for elderly dignity.

In health care practice, attaining the right plan of caring can have an effect on the level of trust, self-assurance and thus, of understanding between patient and health care providers. Furthermore, the patient needs to feel confident and to be acknowledged as a person in order to be able to share information with health care providers. The patient also has social and spiritual needs, such as being involved in activities and communication, and the opportunity of discussing his or her thoughts. Moreover, the patient has physical and physiological needs, for example, eating, hygiene and treatment. Confidence and trust are important factors for a good health care practice. The trust that can happen between a patient and a care provider serves a special meaning, in either way whether the patient has family, friends, or not. Elderly and ill individuals are easily relating their situation to others who can understand them and care for them. The same as with the caregiver, considering a patient's situation from the other side may contribute greater knowledge and understanding, which will allow the patient to feel understood and appreciated. Therefore, carers need to apply their compassionate skills for the desire of serving patients. In such cases, listening to the elderly patient is often enough, and can maintain a good patient-carer relationship.<sup>365</sup>

### **3.3.2. Informed consent**

Respect for patient autonomy is the ethical principle that underlies informed consent.

Informed consent is considered a prerequisite for any medical intervention.<sup>366</sup> Its purpose is to give patients the opportunity to determine what they want to be done and what shall be done, and to make sure they understand the need, outcomes and possible side effects of the health care interventions they have agreed to undergo. The assumption is that health professionals, patients and their families join in a collaborative effort to promote patients' decision making in the process of informed consent.<sup>367</sup> This includes full information about what is planned, clarification of the information already given to the patient, and the dissemination or proper knowledge and education to nursing staff in relation to ethical principles.<sup>368</sup>

For patients to be autonomous when making health care decisions, physicians must adequately inform them about their illnesses and treatment options. The legal obligation to obtain consent for medical interventions was established in American law during the early 20<sup>th</sup> century. However, the term informed consent was first used in 1957 in the case of *Salgo v Leland Stanford Jr Univ Bd of Trustees*. The patient, who was paralyzed after an invasive procedure, claimed he was not informed fully about the risks of the procedure. The court agreed and concluded that a clinician violates his or her duty to the patient if facts necessary to make an informed decision are withheld from the patient. Later cases defined how much information should be given for consent to be considered informed. For example, the case of *Canterbury v Spence* established the reasonable patient standard, i.e., clinicians should provide the information that a patient would need to know in order to make an informed decision about the proposed procedures. The basic requirements of informed consent are that the physician conveys the necessary information to the patient such as the description of the illness, the planned intervention, the benefits and risks, and any alternatives to the

planned intervention. Last but not least, has confirmation of the patient's decision-making capacity, understanding of the information, and voluntary agreement to the intervention.<sup>369</sup>

In certain circumstances, informed consent cannot be obtained. For example, when a patient lacks decision-making capacity, consent must then be obtained from a surrogate. In emergencies, consent is presumed when an advance directive (AD) or a surrogate is unavailable. Furthermore, it is ethically and legally permissible for patients with decision-making capacity to refuse unwanted medical interventions,<sup>370</sup> and thus, a physician's duty is to respect these decisions. Not surprisingly, a patient's refusal of an intervention may be at odds with a physician's desire to do good. Although, the physician's may regard refusing such medical intervention as wrong, however, it is not necessarily irrational.<sup>371</sup> If the physician determines that the patient is adequately informed about the proposed procedure, and the risks of refusing it informally; then the patient's decision must be respected.

### **3.3.3. Decision-making**

Decision-making processes are a central issue in connecting to giving consent. Clinicians frequently care for elderly persons who have conditions like dementia that impair decision-making capacity. However, patients must have decision-making capacity to be autonomous and participate in informed consent. Decision-making capacity includes the ability to communicate a choice, understand the nature and consequences of the choice, manipulate rationally the information necessary to make the choice, and must show reason consistent with previously expressed values and goals.<sup>372</sup> The level of decision-making capacity should be in accordance with the risks and benefits of the decision to be made.<sup>373</sup> For example, the physician should be absolutely certain that a patient who refuses a low-

risk, yet life-saving, intervention has adequate decision-making capacity. However, in some circumstances, patients with impaired cognition do still have sufficient decision-making ability. At times, determining a patient's decision-making capacity can be difficult, especially if the patient or family disagree on the assessment. Sometimes the patient has concerns unfamiliar to the health care providers such as spiritual concerns, or the patient has a psychiatric illness that is difficult to manage. Therefore, psychiatrists, geriatric specialists, chaplains, social workers, and ethics consultants can help determine a patient's decision-making capacity when consulted.<sup>374</sup> At the end, the physician has a duty to protect patients without decision-making capacity from making inappropriate health care decisions. In such cases, the clinician is not overriding patient autonomy because autonomous decisions by the patient are not possible. In these circumstances, physicians should identify an appropriate substitute decision maker.

According to Miles, in health care practice family members may exercise the medical character of paternalistic decision making even when the elder person maintains a high degree of decisional capacity, as long as the elder person does not disagree too severely. In this case, the family concerns might be the maintenance of a high degree of control over the older individual's situation to eliminate and reduce risks, at the same time maximizing protection and safety. On the other hand, this may lead to the reduction of the older person's freedom. Family members who seek to take control often feel that they really know what is in the best interests of their relative. Moreover, in some situations, families maybe more concerned about autonomy than are the elderly themselves. In this case, the elderly are more worried about their own health and safety than in preserving the principle of self-determination.<sup>375</sup>



As a matter of fact, the obligation of physicians to protect patients from harm sometimes conflicts with their obligation to respect the autonomy of the patients to make decisions that other might regards as foolish, unwise or harmful.<sup>376</sup> These obligations can be reconciled when a patient lacks the capacity to make informed decisions. In these situations, it makes very little sense to talk about patient autonomy. Interventions to protect such incapacitated patients thus do not violate the physician duty to respect patient autonomy. In assessing decision-making capabilities, physicians must balance protecting patients from danger with respecting their autonomy. A sliding scale has been suggested for such assessment; the more probable or serious the risk posed by the patient's decision, the more stringent the standard of capacity that should be required.<sup>377</sup> In this event, a sliding scale can be justified because it allows more protection to be given to a patient of questionable mental capacity when the potential harm resulting from their choices is more extreme.<sup>378</sup> The ethical dilemmas associated with elderly care can be a lack of agreement concerning care such as vulnerable patients in inappropriate care settings, or weaknesses in medical support, or deficient information. Associated with them were experiences of being exposed, having to be strategic and living with feelings such as aloneness and loneliness, uncertainty, lack of confirmation, the risk of being threatened or becoming a victim and difficult decision avoidance.<sup>379</sup> The following section provides further insight into the ethical dilemmas and the ethical challenges that affect elderly people care and many stakeholders in elder care.

### **3.4. The notions of dignity and respect for autonomy versus the ethical issues in geriatric care**

The literature suggests that both the dignity and the respect for autonomy of older people are often challenged in healthcare settings. As stated earlier in this chapter, dignity refers to an individual maintaining self-respect and being valued by others. Autonomy refers to individual control of decision-making and other activities. Dignity is undermined mainly through negative interactions between health care professionals and patients, breaching patients' privacy, and insensitivity to the needs and wishes of an older population. Autonomy can be threatened in health care practice when patients are not given enough information on their diagnoses and health condition, or not being able to fully understand their prognosis and make informed decision for their care.<sup>380</sup>

Older people in particular easily become disempowered in health care settings. In reality, elderly need care because they suffer illnesses, weaknesses and incapacities that influence their ability to act independently.<sup>381</sup> Yet, the standard notion of autonomy in bioethics stresses the values of independence and free choice, values that seem rather momentary in the aspect of the losses that cause elderly to need care. However, it is clear that vulnerable individuals will benefit from the protection given by autonomy. Yet, the ambiguity rests in that autonomy supports an idea of healthy and independent persons, where in the reality of elderly care it shows individuals who need buttress and companionship, needs that seems contrary to the ideal of autonomy.<sup>382</sup>

At the end of life, perhaps especially in situations that involve dementia and extreme old age, people seek multiple goods and most often they must trade off one for the other while never achieving one good that satisfies all their values. But without knowing what

values support any person's wishes, desires and what hinders their realization, the possibility for an authentic choice is constrained. According to Holstein, people want continuity, something as close as possible to what they had prior to becoming vulnerable, and dependent on others for help with their daily activities such as bathing, or eating.<sup>383</sup> Elderly people want to maintain to the possible extent, their ordinary lifestyles that make them have the feeling of continuity to be themselves. Philosopher and ethicist Agich describes this form of autonomy as interstitial rather than nodal autonomy. Yet it is the latter the "moment of decision" or episodic kind of autonomy that has gained prominence.<sup>384</sup>

In addition, the ethical issues in aging are complicated because of the individual differences among elderly, which come from differences in personality to culturally rooted behaviors. Some elderly have managed to be in control all their lives, while others may be willingly compliant because they feel overwhelmed by making decisions. Thus, the common understanding of autonomy continues to mean self-directing action, encapsulated in informed consent processes. This observation, however, is far thinner than what a healthy way to aging requires. For example, autonomy is often reduced to making choices in the absence of attention to the conditions that make real choice possible (availability of options, ability to pay for them, choices that are meaningful for ones life), or it is narrowly defined so that it does not oblige us to attend to those things that are truly and significantly meaningful and important for elders.<sup>385</sup> In fact, it means more than eliminating barriers to and honoring choice; personal autonomy is more than unforced choice. However, those standards make some decisions more necessary than others because they preserve people integrity, and reflect motivations that people find honorable.<sup>386</sup>

O'Neill has pointed out that the limitations of actual human autonomy are not taken as constraints on working out the determinate implications with respect to autonomy in actual contexts, but often as aberrations from ideally autonomous choosing.<sup>387</sup> Kapp points out that the pursuit of autonomy for the older adult by trying to prevent guardianship could get in the way of meeting the care needs of the older adult.<sup>388</sup> Autonomy is seen as the basis of human dignity and essential for moral discourse. The ability to act as one wishes, so long as the autonomy of others is not compromised, and to do so without coercion or interference also is fundamental to adult relationships and professional practice. In this regard, Abramson argues that there are only three circumstances under which it is morally justified to curtail autonomy, when the individual's actions do not cause harm to others. *First*, the individual lacks the capacity to make informed decisions or understand their consequences, *second*, the implications of the decisions are far-reaching and irreversible, and *third*, temporary interference ensures future autonomy. However, even under these circumstances, the motivations for curtailing autonomy must be carefully scrutinized along with the qualifications of the decision makers and the caliber of the information upon which the decisions are based.<sup>389</sup>

In fact, with elderly living longer, the number of older persons having disabilities has grown. This has led to increased concern about their risk in the home. In this regard, there is a tendency to underestimate their potential autonomy because of prejudice and stereotypes.<sup>390</sup> In the UK, dignity and respect are key principles of the Human Rights Act, to which everyone is entitled under the law. When a person's dignity is compromised through lack of respect, intentional or not, it is an abuse of their human rights and is punishable by law. Despite this, there are numerous examples of how people's rights are being abused in

hospital wards across the country every day.<sup>391</sup> For example, not being supported by healthcare staff to maintain adequate food and drink intake, lack of respect for privacy on a hospital ward, including mixed-sex wards, and disregard for nudity and modesty during examinations or other health care interventions, not attending to fundamental care needs; for example, ensuring hand and teeth are cleaned every day and people are dressed in their own clothes, excluding the patient during care interventions, not talking to them, or explaining what is happening, speaking to people in an inconsiderate manner, and not taking into account their individual communication needs, such as hearing, speech, cognitive understanding and interpretative ability, the fact that someone experiences hearing, speech or cognitive impairments does not mean they cannot understand and do not need to be involved, communicating in a way that conveys disrespect and a lack of concern for them as individuals, not recognizing the knowledge, understanding and skills of the patient's unpaid carer, and no appreciation of the contribution they can make to the treatment and care, all have failed to keep accurate records and care plans.<sup>392</sup> However, the most common incidents of abuse relate to poor practice, is neglect of care and management, like those mentioned above.

#### **3.4.1. Dependency and vulnerability**

The principle of autonomy is an influential notion on which United States culture and the system of health care delivery is largely based. Indeed, the principle of autonomy has become the foundational principle of health care. Such a concern with autonomy conceals the fact of needing control over aging, illness, disability, suffering, and death. However, Holstein states that to acknowledge the lack of autonomy is to acknowledge that

the human condition is beyond our control; and to give up autonomy is to admit our deep vulnerability, especially as we age.<sup>393</sup> Furthermore, this preoccupation with autonomy relates to independence, since a person's independence and his ability to live independently on others is symbolic of his autonomy. Within the United States, dependence has been strongly associated with weakness, incapacity, neediness, and a lack of dignity; insofar as individuals are able to resist dependency, they are able to maintain their dignity and self-respect. Holstein alleges that this strong emphasis on autonomy as independence has had a very negative impact on aging and aged persons, who find themselves increasingly in need of assistance to bath, go to the bathroom, dress, eat, and get about. It is seen to be shameful and embarrassing to admit that you can no longer perform all these tasks unassisted, and as a result many older adults will refuse for as long as possible to ask for help; instead, they struggle or simply go without their health being cared for, baths or meals rather than ask for assistance.<sup>394</sup>

In addition, individual choice is not the necessary condition for self-respect. Writing an advance directive or giving informed consent is only a fragment of what it takes to know that one's dignity is respected. While there is reason to applaud the achievements that this focus on autonomy helped to create, there are equally compelling reasons to note its limits and propose alternative or perhaps complementary ways to think about ethics and long-term care. The effects of such altered thinking and the behaviors it calls for reside in the good it can bring to patients but also to all participants in the caregiving context.<sup>395</sup> The most striking feature of long-term care is that adult individuals suffering from diseases and illnesses of being old experience a compromised vigor and ability to function that requires

regular care ranging from help in activities of daily living such as housework, food preparation, and hygiene to highly skilled nursing and medical care.<sup>396</sup>

Elders requiring care generally exhibit functional disabilities that frequently bring with them vulnerabilities as well. They exhibit various kinds of dependencies and not the independence so prized by the traditional view of autonomy that stresses values of independence and rational free choice. Traditional treatments of autonomy simply abstract from actual examples of finite human autonomy and contexts of choice and focus instead on idealizations of autonomous action and choice.<sup>397</sup> For example, in a study on the images of aging conducted on behalf of the American Association of Retired Persons, most surveyed Americans of all ages estimated that poverty, poor health, and loneliness were serious problems for people over age 65, even though they are not in practice.<sup>398</sup> Thus, perceptions such as these suggest a greater degree of incapacity and need for assistance on the part of older persons than actually exists. Likewise, there are occasions when the passivity to authority of the current generation of older persons undermines their ability to maintain self-determination once it is threatened.<sup>399</sup>

In 2007, the British Geriatric Society admitted that the National Health Service (NHS) was failing older people, not recognizing the complex needs and dependency of the frail elderly. Such lack of care and respect for the fragile bodies of the elderly in a culture so devoted to personal comfort and costly cosmetic pampering of the body seems especially repugnant.<sup>400</sup> For example, discharging of elderly patients, sometimes in the night without notifying relatives or caregivers, poor care by nurses uninterested and often failing to speak to patients who then feel vulnerable due to being ignored and abandoned.

In the United Kingdom, The Nurses and Midwifery Council Code (NMC) asserts that the people who need care must be able to trust the health institution with their health and wellbeing and then lists the requirements of the caring relationship, such as respect for personal dignity, friendly communication, attentiveness to the patient's needs, treating the patient kindly and considerately, and being an advocate on his or her behalf.<sup>401</sup> The particular dependence and vulnerability of elderly patients requires even more from the carer in terms of patience and composure. Unfortunately, approaches to patients who may be confused or not fully aware of the nature of certain procedures relating to medication and monitoring often become perfunctory and insensitive. The limitations imposed by ageing, which commonly involve sensory impairment relating to sight and hearing, require the careful cultivation of a range of communication skills to provide the kind of comfort that settles worried minds and anxious hearts. In such a relationship, a smile, a word, a glance, and a gentle touch can be powerful expressions of compassionate care. They do not exhaust the demands of care; but without them other aspects of care easily become unfeeling. It is a standard theme in medical education theory that there is a need to inculcate both humane benevolence towards the sick and suffering and also a certain emotional detachment to protect against psychological burnout. It is the former that seems in short supply in contemporary health care.<sup>402</sup> The list of harmful practices identified included, serious neglect of infection and pain control measures; premature discharges from hospital; detrimental moving of patients from bed to bed and ward to ward; not helping patients with eating and drinking, or using the toilet; poor attention to hygiene; leaving some patients on a commode for hours, and failure to change dirty clothing and bedclothes promptly. In this way fundamental aspects of the health, welfare



and human dignity of many individuals are being routinely undermined. Further examples of lack of respect for human dignity related to patients not being spoken to appropriately, failure to provide information or seek consent, patients being left exposed, inadequate attention to pressure sores, mixed sex accommodation, patients being left in pain and in a noisy environment without sleep, and patients being subject to abuse, violent behavior, verbal threats and indifference.<sup>403</sup> In 2001, the Department of Health Standing Nursing and Midwifery Advisory Committee in the UK had reviewed voluminous literature that shows the current standards of care often fail in maintaining older people's dignity, autonomy and independence, and confidentiality.<sup>404</sup>

Thus, care of the elderly is becoming an ever more urgent issue that need to be addressed, in order to prevent suffering for countless vulnerable members of society. To tackle this problem, there is a need for more realistic understanding of the demands on those caring for the dependent elderly, and attention to the cultivation of those qualities of mind and heart needed by health care providers. A Swedish study suggested three themes that illustrate positive and negative aspects of ageing and vulnerability in relation to dignity. They were the unrecognizable body; fragility and dependence; and inner strength and a sense of coherence.<sup>405</sup> The data from the studies provide rich perspectives from older people on their views and experience of dignity and indignity and suggest factors or components that contribute to or detract from dignity in practice.

Demonstrating respect for a person helps to preserve their dignity. Webster and Bryan believe that communication is the mediating factor in maintaining control, independence and dignity. Their research demonstrates that older people value being included in discussions and decisions about their care. This not only enables them to feel

more in control of the situation, but also helps to maintain their independence and, consequently, their dignity.<sup>406</sup> This is also a finding in a study by Baillie; interestingly, in his work, the respectful nurse was considered to be a far more important issue to the patient than it was among the nurses themselves. It is extraordinary that nurses in this study were often unaware of how their interactions could affect people's dignity. A sense of self-worth can be very fragile and is easily damaged, particularly in a healthcare setting, when individuals are subject to abuses of power.<sup>407</sup>

Thus, the view that people have inherent worth plays a major role in everyday medical practice and can greatly contribute to enhance the quality of the doctor-patient relationship. More concretely, this vision helps to keep alive in the minds of health care professionals the conviction that each patient, no matter what his or her diagnosis, is not a case, a disease, or a room number, but a person that deserves to be treated with the greatest respect and care.<sup>408</sup> Care of the elderly is thus becoming an ever more urgent issue that must be addressed to prevent suffering for uncountable vulnerable members of society. Thus, tackling this problem requires a more realistic understanding of the demands on those caring for the dependent elderly, and attention to the cultivation of those qualities of mind and heart needed by caregivers. Above all, it requires a sustained commitment to the moral education of health care providers.

### **3.4.2. Professional-patient relationship**

One of the main difficulties for a person diagnosed with an illness is the feeling of loss.<sup>409</sup> The force of that feeling is often associated with how further the illness has developed. The experience of loss can vary, it can be a change in the outlook as a result

of severe weight reduction for example; or can be related to the loss of a part of the body, such as hearing loss, or loss on the physical movement or mental capacity. In general, elderly people are affected with loss in some sorts. Allied with physical changes, an elderly individual's feeling of individuality can frequently be collapsed. Therefore, elderly persons need for gratitude and caring, and the wishes for respect one's personality from health care professions and family will increase.<sup>410</sup> Caring can be understood as emotional as well as physical intimacy in different effects. Emotional closeness in relation to another human being is an ultimate human need, and therefore, such an absence of social intimacy can reduce psychological health and possibly aging well.<sup>411</sup> The ageing population is placing many health care providers in the front line of geriatric medicine. Ageing and sickness go together, and the consequence is that hospitals are filled with elderly people who require a very different approach from the traditional inpatient or primary care services.<sup>412</sup>

Among the many ethical issues which will concern individual members of the medical profession will be the decision to treat elderly incurable patients; the decision to operate on elderly patients; the dilemma of soliciting the views of a confused or eccentric or demented patient; the handling of a patient who refuses treatment against medical advice; the conflicts, which could arise with selfish or over involved relatives; the unfortunate necessity of occasionally separating dependent elderly couples and many others. Doctors will have additional responsibilities for the accurate documentation of the incidence of diseases in the elderly. It is virtually impossible to predict or estimate morbidity in the elderly. Over the age of 75, it is thought that nearly 65 per cent of patients have some disability; however, there is a hidden incidence of morbidity.

Unreported illnesses such as defects in vision, weaknesses, physical problems and urinary problems are very common but often unrecorded.<sup>413</sup> In part this is an effect of the attitude of patients who regard such symptoms as normal for their age rather than evidence of an active disease process. The health care providers will have the responsibility of documenting and reporting of statistics on disease incidence in the elderly. Hubert Humphrey has been quoted saying “one can judge the morality of society by the way it treats its young, its sick people and its elderly.”<sup>414</sup> Adequate planning and provision with humanity as a large factor in the decision-making on the care of the elderly could lead to a situation where societies, in general, can feel a sense of self-respect.

Advocacy for autonomy of older persons is a challenging opportunity for health care professions today. However, paradoxical situations in the delivery of health care to the elderly, emerging ethical issues, and trends to include clients in the care plans, require basic education and for many, re-education for this role of advocacy for respect for autonomy. Historically, home visits to the sick and elderly were the accepted norm of the helping professions. However, modernization and technological advances in this century have led to the acceptance of more and more institutionalization for care and cure. This societal acceptance poses a special problem for the elderly whose home space has already been diminished by physical impairments and functional decline.<sup>415</sup>

Yet another insidious form of discrimination exists against the elderly is that they are very susceptible to paternalistic interventions. Paternalism may be defined as the refusal to acquiesce in a person's wishes, choices, and actions for that person's own benefit.<sup>416</sup> Both individual and communal beneficence may drive paternalism, but paternalism should be limited and constrained by respect for persons and their autonomy.

Limited paternalism (that is based on beneficence but limited by respect for personal autonomy) can be justified under some conditions where the patient has some defect, encumbrance, or limitation in deciding, willing, or acting; where there is probability of harm to the patient apart from intervention where the probable good effects of the intervention outweigh the probable bad effects of the intervention and alternative modes of action and non-action, and where the least restrictive, least humiliating, and least insulting alternative has been selected.<sup>417</sup> These conditions may be met in the care of various elderly persons, and such paternalistic actions as involuntary hospitalization and forced treatment may sometimes be warranted. But paternalism can be justified only in specific circumstances. It is unfair and disrespectful to attribute incompetence to make decisions to all elderly persons. Both justice and respect for autonomy dissolve that rationale for indiscriminate paternalism. Childress argues that it is morally imperative to attend to individual differences, rather than to treat the elderly, even the infirm or sick elderly, as a class.<sup>418</sup> Childress argues that paternalistic interventions cannot be justified in relation to such a class, only in relation to individuals. Thus, we need several independent moral principles, such as individual and communal beneficence and respect for personal autonomy. Both individual and communal beneficence may drive paternalism, but paternalism should be limited and constrained by respect for persons and their autonomy. It is not time to repudiate autonomy unless it is wrongly conceived as the single, exclusive, or overriding principle of biomedical ethics. The danger of replacing one principle by another is evident when we consider the importance of both beneficence, which supports paternalism, and respect for autonomy, which limits and constrains paternalism. Paternalism motivated by individual or communal benevolence, but

unlimited and unconstrained by respect for autonomy becomes cruel, but respect for autonomy, uncoupled from benevolence, becomes indifferent to the dilemma of others. It is important to avoid both temptations and it is possible to do so by maintaining a proper tension or balance between care and concern, on the one hand, and respect for persons autonomy, on the other.<sup>419</sup>

In fact, human beings are a unity and cannot be fragmented, and this unity includes the need for dignity and respect. Therefore, the paternalistic attitude that older people do not know what is best for them can be replaced with the more positive attitude that older people can be taught self-determination and adaptive problem solving skills.<sup>420</sup> Health care professionals attitude and behavior have the potential to enhance dignity when care is individualized and people not stereotyped, when appropriate terms of address are agreed, when time and care is invested in helping people to dress and be trained as they see fit, and when communication is improved to facilitate collaborative and patient-centered care. Patients feel that care that contributed to dignity required appropriate use of language, empathy, and kindness. In the Dignity and Older Europeans Project, older people emphasized the importance of health care professionals and others showing respect and recognition, such as being treated as an individual, being addressed by care staff appropriately, maintaining a respectable appearance, and language barriers between care staff and service users.<sup>421</sup>

Researchers have found major problems with patient-health care professionals' communication.<sup>422,423</sup> Health care professionals frequently fail to elicit patients' concerns, for example, physicians interrupt patients, on average 18 seconds after patients begin to describe their reasons for the consultation. Furthermore, advance care planning

and end-of-life discussions between clinicians and patients are sparse.<sup>424</sup> As a result, it is not surprising that ethical dilemmas may arise because of poor communication between health care providers and their patients or surrogates. Nevertheless, research studies, including randomized trials, have found that effective patient-clinician communication is associated with greater patient satisfaction and compliance and better health outcomes.<sup>425,426</sup> Also, effective communication is associated with fewer malpractice claims, and may prevent ethical dilemmas.<sup>427</sup> Accordingly, effective patient-clinician communication maximizes patient autonomy, and it goes beyond informed consent and maintaining confidentiality. Health care professionals have an ethical duty to treat patients in a dignified, courteous, and respectful manner.<sup>428</sup>

Fortunately, clinicians can learn skills to improve communication with patients related to opening the interview, information gathering, relationship building, and conveying medical information such as tests results and diagnoses. When opening the interview, clinicians should endeavor to learn about the patient as a person, for instance, (who they are, their values and goals, etc.). Also, the patient should be allowed to describe his or her reasons for the consultation without being interrupted.<sup>429</sup> Notably, the average time for a patient to articulate his or her list of concerns is 60 seconds.<sup>430</sup> After all the patient's concerns have been aired, the clinician and patient should jointly prioritize them. Patient-centered interviewing requires little time and effort.<sup>431</sup> Other factors and conditions may inhibit effective communication between elderly patients and their physicians including hearing loss, cognitive impairment, and social isolation. To fully discern the needs and maximize the autonomy of their patients, clinicians are obligated to address these conditions and factors.<sup>432</sup>

The literature shows that a key means of tackling poor attitudes by staff towards older people is through extensive and continued training. One study reported that more positive attitudes towards older people were found among nurses working in elderly care than among those working in acute care (which covers all ages) and attributed this to a more specialized training.<sup>433</sup> Another study reported more favorable attitudes towards the care of older people among students attached to a geriatric ward than among those attached to a general ward.<sup>434</sup> It seems, then, that training in geriatrics has a positive effect on the attitudes of staff. In fact, the evidence shows that mere exposure to certain groups of older people is beneficial. Older students and those with grandparents as role models have been found to have better attitudes towards older people.<sup>435</sup>

Indeed, several authors have written about the importance of healthcare staff being exposed to older people who are healthy as well as to those who are patients.<sup>436</sup> Increased and improved training and exposure to older people is also likely to do much to raise the status of geriatrics. Improved status is likely to have a positive impact on attitudes and encourage more individuals into the field, which in turn will benefit older patients. Such training should be mandatory for all health service staff not limited to those who work only with older people.<sup>437</sup> Staff who are trained and experienced in geriatrics will be not only better equipped to treat older patients but also more sensitive to issues surrounding an older person's dignity and autonomy.<sup>438</sup>



### **3.4.3. Physical and social environments that foster the health and well-being of older people**

Nordenfelt claims that if dignity entails rights that should be respected, then there is a duty for all of us to respect these rights. However, in some cases the rights of an individual may be violated. For example a concentration camp; according to a common mode of expression, prisoners in such a camp are deprived of their dignity; they are degraded by the extremely inhuman treatment imposed by the camp officers. There is, however, something more at issue in the case of the concentration camp and similar examples of inhuman behavior. What frequently happens is not just the occurrence of a subjective feeling of humiliation on the part of people who have been humiliated.<sup>439</sup> There may also be a changed public perception of these people. There is a change in public status; the person who is assaulted and humiliated by somebody can be looked down upon, simply because he/she has lost the image of integrity, of strength and of being an autonomous person. But it is not only assault and humiliation that can degrade people, in fact there are other external events and internal processes that can do so. This is highlighted by Peter Kemp, "Dignity might be considered as lost in extreme illness and in violent suffering... The loss of dignity here is the loss of a respectable body."<sup>440</sup>

The dignity referred to here has nothing to do with the changes that pertain to the sick, the handicapped and the elderly. Some of these persons may indeed lose some legal rights, for instance the right to drive a car or the right to continue in their profession, but they may also acquire a few new rights, such as the right to travel free on public transport. The issue here is something much more sensitive, which has to do with public perception. There is a value-scale possessed by many people, although a highly vague

value-scale and one which varies from individual to individual, which is such that the sick, the handicapped and the elderly are perceived as less valuable than healthy working adults. People think more or less highly of a person because of the person's achievements, the physical, intellectual and perhaps also the emotional and moral ones. People do not think highly of the sick and the weak; sometimes they include the elderly in such a negative evaluation. They often look down on them simply because they think that these persons lack certain capacities and understandings, and possibly because they are old or they do not look attractive. And thinking in this way, these people degrade the insane, the sick and the handicapped on the ranking of public status. For the most part, this is a social fact in many cultures on this earth.<sup>441</sup>

Culture plays an important role in how dignity is perceived and how it is maintained. The individual acquires values, such as privacy, and respect and how to be addressed, sets standards according to these values and from these standards judges what is acceptable. For example, the appropriate amount of eye contact that should be used in an interaction can vary according to culture. In Western culture intermittent eye contact is required to show that one is paying attention to another person. In other cultures eye contact is avoided when speaking to a person deemed to be superior. If these standards are met, an individual develops a sense of pride, has high self-esteem, and feels worthy and valued. If standards are not met, self-esteem declines and the person feels unworthy.<sup>442</sup> The perception of dignity changes with the passage of time. For example, compare the values of modesty or decency in dress sense held by older people. That which is deemed dignified or appropriate differs markedly between the two. This relates

to feelings about the body and what constitutes an acceptable appearance. Therefore, an individual has expectations about how he/she wants his or her dignity maintained.

Furthermore, Newman and Brown point out that autonomy is not one-sided. It implies responsibilities as well as rights.<sup>443</sup> Thus the elder, the family, other informal caregivers, and professionals all have rights and responsibilities in the network of interaction. By extension, the rights of each must be honored by others, and in so doing; all must be responsive and responsible to each other.<sup>444</sup> The culture of care indicates factors that suggest in general the shared beliefs and values concerning the nature, style and organization of care. Thus elderly people wish for the opportunity to be involved in their care, to express their autonomy, to be allowed to give or withhold consent, and to be treated as individuals, in an atmosphere that respected cultural differences and offered confidentiality.<sup>445</sup> The Department of Health in the United Kingdom, report that if the culture of care is positive rather than defensive and focused on therapeutic goals and patient well-being, then complaints processes will be viewed in practical terms.<sup>446</sup>

Concerns regarding the culture of care seem to reflect dignity of identity, as these are the concerns of the autonomous, rational individual seeking to preserve self-respect and self-identity. They are underpinned by concern for human dignity, as this provides the basis for efforts to involve patients as much as possible even when this is difficult, and to provide individualized care wherever possible even if this has to be inferred from secondary information, for example a patient suffering from advanced dementia. Another theme relates to the wide range of specific care activities that have the potential to promote or obstruct dignity, for example, to actual procedures or actions, such as bathing, feeding, dressing and so on. Respondents to the DH survey mentioned these frequently as

examples of undignified care, describing patients not being given help with meals or drinks, not being dressed appropriately, or being placed in situations where privacy was ignored, and similar concerns have been raised in many other reports, for example in the media.<sup>447</sup> Such indignities by definition would be inflicted on the most dependent patients, and vulnerable patients, often on those who lacked capacity through dementia.

Individual patients' preferences also appraise the importance of dignity of identity and to nursing responses that engage with patients in their care. Probably it is not possible to develop a set of necessary and sufficient conditions of the essentials of human dignity. Nonetheless, human dignity remains a valuable concept within its own boundaries. In the end, the notion of dignity demands an appreciation of worth and a related belief that we should treat individuals with respect and appropriately for their value as individuals.

Patients and medical professionals have expressed several concerns to situations where people sensed that they had or had not been treated as being worthy and had or had not been shown respect for their dignity.<sup>448,449</sup> The attention of the full analysis of patients' identity and their versions of experience comes in the way they choose to demonstrate the sort of treatment that does or does not count as dignified care in their view. These varies from direct neglect, for instance, when a patient is left in a filthy bed, to being given appropriate chances for full participation and involvement in making decisions about their health care. It is not unexpected that much of what is described as adding to dignity in care could be categorized under the heading of individualized care. Government goals and routine, staff shortages, or familiarity within the working environment can all contribute to the care provided. In the chaos of a busy ward it is possible to unintentionally neglect those who need the most care.<sup>450</sup>

In any society, the appreciation of the value of people is a necessary ground for the survival and maintenance of the institutional services. According to Gallagher, the relationship between skill and the quality of care is already supported in the literature;<sup>451</sup> however, detailed work is essential to study the specific problems of undignified practice. The culture of care is complicated and is influenced by many aspects, some of which will go beyond other issues, such as attitudes and behaviors of work.<sup>452</sup> Healthcare support workers (HCSW) play a significant role in maintaining dignified care. Increasingly, it is the HCSW who is charged with providing the individual's fundamental care needs.

Fundamental care, which is seen by many as basic, is in fact the very essence of nursing. The effect on patients' welfare when such nursing care is neglected or shunned is catastrophic. The environment may not lend itself to a person-centered approach; it could be increasingly task-orientated and target-driven, to the detriment of those being cared for. Such environments can cause stress and anxiety among those trying to provide quality care. Dignity is a standard by which we measure conduct, both our own and others. It is not an ideal, if we do not provide care with respect, then we lack dignity. In our hearts we all know what is required of us, the challenge is being brave enough to do it.<sup>453</sup>

In actuality, the development in human lifetime creates a need for proper social presence; it is similarly true that elderly face certain age-related challenges that make it difficult for individual's abilities to achieve such involvement. Just as the President's Council on Bioethics described in a recent report, "while people are living healthier into old age and doing so on a mass scale, there remain many difficulties, both psychic and physical, that eventually come with growing old."<sup>454</sup> Therefore, there is a need to

improve a social duty to supporting the abilities of older people, although focusing on the limitations and losses of both physical and personal health that often characterizes the evolution into old age.<sup>455</sup> We can become impervious to the patient and his or her suffering; we may only see age, disease, incontinence and relentless needs. Often, the individuals who require the greatest care are most deprived of it.<sup>456</sup> Everyone, irrespective of age or social status, has the right to be respected. It is easy for healthcare workers to become complacent about the nature of their work and environment. Every healthcare worker should consider what it is like to be admitted to hospital. Fear of the unknown and loss of control accompany a nagging doubt that you might never return home. These people have no choice but to put their trust in those who are there to care for them, and in return they anticipate and deserve kindness, consideration, competence and compassion.<sup>457</sup>

### **3.5. Conclusion**

To recognize how the notion of human dignity operates in bioethics, the discussion in this chapter explains the distinction between the intrinsic dignity of the human being and the moral dignity. It was identified that the inherent dignity, as it is attached to the human condition, is the same for all, and cannot be gained or taken away.<sup>458</sup> Dworkin uses the phrase human dignity to indicate that it means “the intrinsic importance of human life” and commands, “people never be treated in a way that denies the distinct importance of their own lives.”<sup>459</sup> On the contrary, moral dignity does not refer to the individual’s existence itself, nevertheless it relates to the individual’s behavior and their ability to freely choose and to promote their own lives usefully and the

lives of others. In fact, the idea that the person's freedoms can be limited to ensure respect for human dignity is not new, nor definite to the activities dealing with clinical practice. On the other hand, such limitations are somewhat common in legitimate endorsements, both at the domestic and universal level. Therefore, it is more actual to explain both views as being two aspects of the same need to ensure respect for individuals, rather than suggesting dignity as restraints as a new concept and resisted dignity as empowerment.<sup>460</sup>

The lack of respect shown to vulnerable and sick older people in hospital wards is often in the news. The fact that we may be one of these vulnerable and helpless people in our own old age may be a difficult idea, and perhaps this is why we might view the patient as an object, not the same as us, and not experiencing things like us. Furthermore, having dignity is associated with respect for autonomy and the feelings that we have about ourselves. People have dignity when they believe that their life has value and meaning for others. For many elderly being hospitalized is a stressful matter. Because it involves the feeling of dependency, humiliation of disease and ageing, and the feeling of disrespect due to the behavior of some health care providers. Today, being old does not merely present issues of physical survival. In fact, the improved of human longevity means that today old age establishes a distinctive and lengthy life phase for which the demands of purpose and the individual's role in society must be met. Currently, the way old age became somewhat different than the past. The differences found in the longevity of life and health expectation, and in the elderly's higher accomplishment of educational level.<sup>461</sup> This chapter attempted to characterize the notions of dignity and respect for autonomy, which in its turn entails a set of rights that other people must respect. Elderly

people are individuals with unique experiences, needs and preferences, and these elements may grow stronger with again. Therefore, caring for older people should be the core of health care sector. The notion of dignity is the universal equal value of all human beings to which are attached the specifically human rights. And regardless of what age a person is in, the integrity and respect for identity should be a core value in health care practice.

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<sup>281</sup> Alfred I. Tauber, "Historical and Philosophical Reflections on Patient Autonomy," *Health Care Analysis* 9, no. 3 (2001): 299-319.

<sup>282</sup> Ibid. 299-319.

<sup>283</sup> Cicero, *On Duties*, trans. Miriam T. Griffin and E. Margaret Atkins (New York: Cambridge University Press, 1991), xvi.

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- <sup>460</sup> Andorno, "Human Dignity and Human Rights," 9.
- <sup>461</sup> Moses, "A Just Society for the Elderly," 338

## **Chapter 4. The ethical framework in Islamic countries; how the concepts of dignity and respect for autonomy are framed concerning elderly health care versus Western countries**

### **4.1. Introduction**

The concept of patient autonomy has gained much popularity during the last three decades. Islam upholds the intrinsic value of the underlying concept of patients' autonomy, however, differences emanate in the apprehension and practical application of autonomy. The World Health Organization (WHO) considers that the expectation of autonomy is universal, but it has also noted cultural diversities in its understanding and applicability.<sup>462</sup> Many health care associations have acknowledged patient's right to choose an appropriate treatment from all available options. Medical practitioners, as well as family members, should respect a patient's autonomy through issuing essential information and motivating the patient to take control in the decision-making process. Currently, informed consent is recognized as a foundation of medical practice. According to Schultz and Levi, informed consent is defined as a discretionary and explicit agreement made by a person who is deemed competent to make an informed decision concerning a proposed act.<sup>463</sup>

According to Fry, Veatch, and Taylor, patients and medical practitioners in Western society believe a patient's autonomy must be respected.<sup>464</sup> Western bioethics prioritizes the essence of the personal decision by arguing that patients should be left to make decisions concerning themselves. While this point of view is fundamental, most patients in the United States believe it is necessary for clinicians to be part of the decision-making process in consultative capacities. Conversely, Webster and Bryan

identified that, in the Muslim society, patients' autonomy is essential, but it is the responsibility of the family, caregivers, and policymakers to ensure that the needs of the elderly are appropriately addressed,<sup>465</sup> and to lessening the role of the clinician in the process.

Despite the functional differences in Western and Islamic bioethics, they are universal in the application of bioethical principles.<sup>466</sup> The Western approach is a contemporary phenomenon developed in the early 1980s to examine issues in clinical practice and biomedical studies. It was anchored in natural philosophical factors based on human reason and declining moral values related to religion. The Western model was founded on the individual's right to decide his or her own destiny. However, this approach encountered several challenges that called for moral considerations. The principle of autonomy can be found in the Quran declaration: "We have honored the sons of Adam; provided them with transport on land and sea; given them for sustenance things good and pure; and conferred on them special favors, above a great part of our creation."<sup>467</sup> The distinction and honor that these words of God (Allah) have placed on human beings to administer their duties and responsibilities make humans superior in this respect to all other animate beings. A human being has been furnished with skills, an intellect, for instance, personal choice, and awareness of the truth or reality, theoretical and rational understanding of science, language, and many other talents, which are offered by God for the nourishment and development of every part of human nature. Webster and Bryan declare that the Islamic approach generates its resources from spirituality.<sup>468</sup> God (Allah) is the guiding force that helps people acknowledge moral concepts precisely applicable to health care. A common basis of belief and norms leads to

a monotheistic culture focused on building harmony in one's life, family, and community by adhering to the will of God. According to Webster and Bryan, in Islam, the bioethical decision-making is guided by religion since it describes the role of the self, the family, and the health care providers. No event in Muslim society is considered entirely secular.<sup>469</sup> In contrast, in the Western culture, the concept of autonomy facilitates individualism and self-control. These expectations block a third-party from offering support unless the individual grants permission. This expectation of the application of the principle of respect for autonomy can be challenged in Islamic countries due to the way health care and society are structured.

Confucianism for instance, is a profound cultural and philosophical phenomenon in several Islamic countries, which sees the principle of autonomy differently than Western traditions. The view of Confucius on humans takes two dimensions: the vertical and horizontal dimension. While the vertical dimension views people as rational beings and independent, the horizontal dimension views people as autonomous, yet as relational since they must participate in enhancing the welfare of others.<sup>470,471</sup> In this light, a person is seen as born and civilized by education and experience to become a relatively autonomous being. Islamic bioethics, in contrast, is anchored on obligations to care for the elderly and social wellbeing for all. Individual considerations are subordinate to community interests. This claim contravenes the United Nations Educational, Scientific and Cultural Organization (UNESCO) declaration that states personal benefits should be prioritized over family or community interest.<sup>472</sup>

Other ethical issues associated with elderly care are involving frailty and weakness, which have been referred to the loss of several functional abilities such as

physical, mental, and social. An important feature of frailty is the significant potential for quick deterioration of functional activities. The resultant weakness can threaten dignity and respect for autonomy by decreasing an individual's rule over his/her life; thus, remaining beneficial and not being viewed as a burden on others is part of preserving dignity. Dependency created by frailty directly challenges the healthy balance in life between giving and receiving, and, therefore, social involvement is an important factor in welfare.<sup>473</sup>

Moreover, resource utilization is a common ethical dilemma faced daily by health care practitioners. Resources are described by contributions used to enable patient care, whether services, financial, or the type of care provided. In the United States, for instance, the aged population is viewed as a burden on the economy since they require more medical care resources, while being less productive.<sup>474</sup> These resources include funding, bed spaces, and human labor. The question of how clinicians should deal with such patients, compared to other patients who can utilize the resources better, arises. The elderly are seen as a group that is ailing. Thus, keeping them on life support machines seems less important when these resources could be channeled to younger patients with higher chances of survival. Contrary to this opinion, Islamic religion does not view one person's life as more valuable than others, regardless of age, gender, religion, or race.<sup>475</sup> Furthermore, Webster and Bryan claim that the Islamic values regarding care for the elderly should not adopt the Western perspective that views the elderly as problematic to the community. The elderly must be assisted in making decisions while respecting their dignity.<sup>476</sup>

Western bioethics advocate for respecting autonomy that encourages choice covering all areas of social, health and individual life, aspects that are largely ignored in the Islam cultures. Conversely, in Islamic bioethics, for an individual to behave autonomously, people should consider the essence of God, the society, and the patient. Therefore, this chapter will explain the health care practice perspective in Islamic countries that incorporates cultural values in understanding patients' autonomy and dignity, and the patients' roles in health care. The first part will examine the place of Islam concerning dignity in the care of the elderly versus clinical practice, followed by the diminished principle of respect for autonomy concerning elderly health care and the difficulty of being autonomous, not because of the Islamic religion but due to the cultural traditions. Subsequently, the discussion will move to demonstrate the role of both concepts and the ethical dilemmas involved in treating older persons differently from other age groups, versus family traditions of caring for older people including decision-making processes and vulnerabilities. Furthermore, age and gender inequality in Islamic countries will be argued, concerning the different perspective among generations, and the inequality involved with women's health in many Islamic countries. The focus will be on the influence of Islamic religious faith and custom on the aging experience; and one should be mindful that Islamic bioethics is attached to the religious ruling. However, sometimes a necessary religious law can be overlooked in certain contexts. This dynamic feature means that Islam can undoubtedly adjust to science and biotechnological developments. As discussed in chapter two, this dynamic feature has paved the way for authorizing certain bioethics law in Islamic countries.

Population aging is a universal fact affecting both developed and developing nations, and ethical dilemmas involving elderly care have recently come to the front. Pursuing this concern further, the second part of this chapter examines the distinctive cultural concepts of care services for these groups in Islamic culture versus Western culture. The caring issues can create interesting problems in the way elderly care plans are determined; therefore, the physician-patient relationship in Islamic countries will be examined to understand how Muslim people and health care professions respond to the challenges of modern health care. Moreover, the problems of families and tradition when caring for the elderly can increase feelings of vulnerability and dependence, due to the lack of awareness of the concepts of both dignity and respect for autonomy. Also, health care institutions can be insensitive to cultural needs, and health providers, who are the gatekeepers, can lack knowledge or understanding of the various groups they assess. Thus, language barriers, isolation and loneliness will be considered. Finally, the discussion will explore the ethical issues associated with health care access, and how burdens to the family, health care providers, and institutionalization can diminish one's dignity and respect of autonomy in older individuals, and force them to rely on family for their care.

#### **4.2 Ethical dilemmas in geriatric care in Islamic countries**

Islam has usually encouraged the practice of medicine and biotechnology to eliminate or minimize human suffering.<sup>477</sup> Throughout the world, Muslims are motivated to utilize modern biomedical advancements, and in various situations, they might favor western medicine over other practices of care.<sup>478</sup> Modern geriatric care is growing

increasingly multicultural and diversified. Geriatric care is far more complicated than merely taking care of elderly patients. Due to the diminished level of competence among elderly populations, the patient unit in Islam societies is extended to cover the patients' family, cultural, and religious factors. Consequently, physicians meet patients from a variety of cultural and religious foundations, and they must navigate through various barriers to offer sensitive care. However, since the aging population is more vulnerable to terminal and complicated ailments, this part will analyze various ethical dilemmas associated with the right to choose medical treatment and being honest with patients about their conditions.

Islamic societies believe that in cases in which the patient is incapacitated to make decisions, the physician or a family member may need to identify the patient's preferred course of action. Furthermore, in Islam, if an individual acts autonomously, he may cause risks to himself or others; therefore, it is the obligation of the physician, or the society, to prevent such acts to avoid undermining the collective wellbeing. For instance, unhealthy lifestyles and actions that threaten personal and public well-being such as substance abuse and environmental pollution are restricted in Muslim society.<sup>479</sup> In contrast, in Western society, these activities are enclosed within the spectrum of personal autonomy and are thus viewed as personal decisions. Islamic culture undermines individual autonomy if the consequences are detrimental to others. In Islamic society, people are granted the right to make choices, but it becomes problematic when such choices influence one's health or threaten death. Anorexia, for example, is a common eating disorder among patients who want to starve themselves to death. Dealing with such challenges becomes increasingly difficult for a physician. According to Islamic society, it



is the physician's moral obligation to override freedom of choice and intervene for the best interests and welfare of the patient. It is always desirable to give the patient hope since it generates belief to see life from a positive perspective. Islam does not authorize an individual to act as he wishes. Rather, it confines them within firm guidelines, primarily from the Quran and the Sunnah.<sup>480</sup> According to Sachedina, ethics is believed to be the primary segment of every act of a Muslim. Consequently, the physician-patient interactions and ethical values are more safeguarded in the Islamic approach.<sup>481</sup>

Furthermore, requests to uphold the truth about a patient's condition are a very traditional approach to the family of the elderly patients. It is also possible for clinicians to provide false or misleading details to patients. Lying to patients might be acceptable in cases in which the decisions favor the well-being of the patient.<sup>482</sup> For example, dealing with alcoholism or substance abuse among elderly patients is challenging, and giving warning to substance addicts regarding their health can substantially help them avoid substance use.<sup>483</sup> At some point, clinicians understand that addiction will result in terminal illnesses such as cancer or even death. The ethical dilemma arising here is whether addicted individuals should be made to believe that they are dying soon. Dobrof, Disch, and Moody refute such claims by arguing that lying cannot be of any benefit to the patient; rather, they should be told the truth and left to make decisions regarding their lives.<sup>484</sup>

Another issue is found in a study of Low, Yap, et al. According to their observations, in Singapore, most elderly people have not heard of the existence of an advanced directive, or its concept, despite having had personal experience with hospitalization, acute illnesses or witnessed it being implemented with a family member

or friends. Most of them believe that issues related to future illnesses were better left to God or destiny, and they abstain from planning for the future. The study shows that the willingness to consider future illness and the end of life is not worldwide.<sup>485</sup> While an individual's right to know about the diagnosis and health conditions is the custom in Western countries, this knowledge becomes necessary mainly if a person were diagnosed with a terminal illness.

Furthermore, it was found that race, ethnicity and cultural values have a significant function in advanced-care planning. Malaysia, for example, has a mixed ethnic population. Islam is the most widely acknowledged religion with 60.4 percent of the population, and studies have observed that religion is highly allied with ethnicity in Malaysia. A study conducted by Htut, Shahrul, and Poi showed that the majority of older Malay Muslims wish to die at home. The main reason given was because they could obtain final religious customs from their family.<sup>486</sup> The examination of the study indicates that religion has a positive impact on the adjustment process at the end of life, at both the individual and social levels. Religion works as an essential subject of integration in old age, if it had been part of the childhood socialization process and has been continued throughout the individual's life. The social support system can provide avenues for the elderly to play a meaningful role in religious-oriented activities, thus relieving the sense of loneliness to some degree. Moreover, such activities have accompanying tangible and intangible benefits, which serve to enhance the self-image of the elderly. These factors were observed in cultural studies of Malaysians and Singaporeans.<sup>487</sup> As mentioned earlier, Muslims view the process of aging as the Will of God. Thus, it is a time for retribution for past sins in preparation for the end. Showing tolerance,

helpfulness, benevolence, and mercy are qualities that are promoted among the older generations, and to understand the Muslim patient better, one has to be acquainted with the concept of “Ihsan,” which is validated by religious precepts and beliefs. The concept of “Ihsan,” in the spiritual sense, implies the attaining of merit or reward for good works performed. The person of distinction is a person who possesses the characteristics and motivations associated with the concept of “Ihsan.”<sup>488</sup> Therefore, in elderly family relationships as well as in community relationships with friends and neighbors, a strong consciousness of practicing these traits exists. The few mentioned examples are some of the ethical challenges that physicians encounter every day while handling geriatric care in Islamic societies.

Tham’s study of people in Singapore shows that religion can be an active thread in the integrative process at old age. Religious beliefs, if transmitted during childhood and upheld during the middle adult years, can provide a link for integrating the individual’s past life.<sup>489</sup> In the Singaporean context, religious beliefs and practices are the sources of meaning and integration in the majority of patients. These issues show that person, society and cultural settings in different healthcare context may impact the maintenance of patient dignity in various sociocultural contexts. The implications of these connections are explored in the following section, which will demonstrate dignity in clinical practice and the elderly view of the concept.

#### **4.2.1. Dignity in the care of the elderly versus clinical practice**

Dignity is the state of feeling important, honored or acknowledged.<sup>490</sup> Despite the devotion and growing focus on dignity within the Islamic health policy and professional

codes of practice, dignity proves hard to transform into action when caring for a patient, particularly in geriatric care. Respect for the dignity of patients has to be balanced with respect for the practitioners' self-respect. Several scholars indicate some of the common practices that contribute to the lack of integrity for patients. These cases include leaving patients in poor conditions, and pushing and handling patients in a rough and cruel manner that could result in pain. Indeed, elderly patients need a lot of attention, need to be seen regularly or talked to, so they can feel acknowledged. One of the basic human rights concepts is dignity;<sup>491</sup> it is the upholding of what is wanted by any individual regardless of their status.<sup>492</sup> Dignity for patients is an essential part of the care that has many years been declared as a fundamental concept in medicine. In a statement on the supporting of patients' rights, the World Health Organization (WHO) asserts: "Patients have the right to be treated with dignity, which should be rendered with respect for their culture and values."<sup>493</sup> Nevertheless, research have been implemented to explain the description of dignity, yet it is still an intangible concept that is not well-defined.<sup>494,495</sup> In the same way, the United Kingdom Health Department states, "There is no clarity about what dignity is and what minimum standards for dignity should be."<sup>496</sup>

Also, research and articles have shown that preserving patient dignity in healthcare is not satisfactorily maintained.<sup>497,498</sup> According to Shultziner, human dignity plays the role of the highest value on which all human rights and responsibilities depend; however, the meaning, content, and basics of human dignity are never clearly well-defined. Rather, their assertions of human dignity reflect a political agreement among groups that may well have quite different beliefs about the meaning of human dignity, its sources and what it involves.<sup>499</sup> Human dignity sets out as a placeholder for whatever it is

about people that accredits them with fundamental human rights and self-determinations. Additionally, advocating patients' dignity and their rights in health care context has been the goal of the World Health Organization.<sup>500</sup>

Regardless of the fact that nothing particular influences dignity, there are some factors that have been submitted. According to the Royal College of Nursing, institutional culture, physical environment, and worker attitudes may also impinge dignity.<sup>501</sup> However, several studies promote this interpretation by demonstrating that maintenance of dignity in a healthcare context is affected by a mixture of factors.<sup>502,503</sup> The academic and experimental works of dignity recommend a collection of theoretical relationships between dignity and other values as respect for autonomy, confidentiality, and self-sufficiency.<sup>504,505</sup>

Most research has found that the deterioration of dignity has emerged from the lack and from the change in clinical education.<sup>506</sup> Currently, a tendency has emerged to reduce the cut on the burden of the health care provision based on individual human rights. Patients are concerned with making decisions on their health, unlike in the past when patients were isolated to suppress the rights of the few for the benefit of the larger population. Now this action is not morally acceptable in the Islamic States or across the globe. This isolation reflected a lack of dignity for patients suffering from various diseases; for instance, discrimination for patients infected with HIV/AIDS was prevalent worldwide; until the United Nations policy prevented isolating those patients. Similarly, the argument for committing a mercy killing still revolves on whether patients have the right to die when they feel they cannot fight anymore. Unlike in some parts of the Western society, where patients might be given the opportunity to commit euthanasia, the

Islamic society believes that life is a sacred gift to humanity by God, and only He has the authority to take somebody's life. Instead of letting patients die if they wish to die, Islamic ethics advocates that elderly care is about facilitating quality care and assisting the elderly to live longer through available resources and nursing care towards the aged.

The completeness or roundedness of integrity differs from mere personal self-sufficiency. While referring to the self in its wholeness, integrity also points beyond the self toward the person, the ideal, and the transcendent that gives identity to the individual life.<sup>507</sup> Some physicians may be able to obscure this reality in polite conversation among themselves or with the general public. But on the receiving end, many elderly patients will paradoxically accept it and even actively collaborate with medical personnel in their mistreatment, because these patients share the underlying social norm that their worth is diminished since they are old and frail. For such elderly patients, demanding the right to die can serve as a final affirmation of their allegiance to the social ideal of youthful, vigorous activity both by actively choosing to die and by lifting the responsibilities of their dependency from others who seem to them intolerant of their reliance. The burdens of adequately caring for frail elderly people extend, of course, beyond directly participating medical personnel.<sup>508</sup> Evidence suggests that elderly disabled persons seek death not because they find their impairments unendurable, but because they are trapped in a dehumanizing social setting.<sup>509</sup> What makes life unbearable for such people is not their impairments, but the social world that subjects them to physical confinement and denies them from even the decision-making power over their lives. Therefore, the disabled older person's misery is caused by the choices and policies of other persons. The person may seek death as the only alternative to living without basic dignity. In this view,

the ethical solution is not to allow or assist in the individual's death, but to free the members of this minority group from the oppressive conditions under which they are forced to live by implementing policies that promote independent living.<sup>510</sup> Therefore, when cultural gaps between health care providers and families are deep, highlighted by language barriers and different experiences formed by social class, discussing the complicated modifications on the path from life to death will always become an intimidating challenge and even more difficult. Furthermore, the challenges are horrendous when healthcare providers and the patient's families have entirely different expectations and goals.<sup>511</sup>

From the 6<sup>th</sup> century and the earliest country of Iran, the Cyrus Cylinder, which is a written declaration in the name of King Cyrus the great, is believed to present the oldest code of human rights.<sup>512</sup> The writing states that all people must have autonomy of thought and choice, and everyone should respect each other. Moreover, it stresses the need to respect human dignity. In 2002, Iran issued the first patients' bill of rights, similar to the international descriptions but not precisely in agreement with Iranian culture. Even so, the statement indicates respect for individual dignity is located in all hospital areas. Yet patients are not aware of the concept or its contents, and no facility is responsible to ensure that its precepts are being respected. Even though the studies of patients' rights in Iran have been increased, and precedence has been set for any quantitative or other aspects, still no qualitative research has been devoted to patient dignity. Just lately, research has begun to form a code of ethics for the nurses in Iran.<sup>513</sup> In fact, an absence of respect for patient privacy was a frequent subject among elderly people in Iran. This matter covered two kinds: indecent body exposure and mixed-gender places. As reported

in a study presented by Ebrahimi, Torabizadeh, et al., based on elderly perception on dignity, having their body visible to others shows disrespect for their dignity.<sup>514</sup> For example, hospital gowns leave some parts of the body uncovered.<sup>515</sup> Therefore, elderly emphasized the avoidance of unnecessary undressing into an unsuitable outfit that renders their dignity in peril. Several further studies report that elderly people underlined that being uncovered in a hospital or a mixed-gender place, whether to a healthcare provider or a roommate, made them feel humiliated.<sup>516</sup> This fact verifies the outcomes of several studies that respecting privacy is critical in supporting patient dignity.<sup>517,518</sup>

Another issue that elderly people reported and referred to as damaging their dignity is the existence of the opposite sex, whether hospital employees, mates or guests. Patients felt awkward when they were alone with patients of the opposite gender in the same room. According to the researchers of the study, approximately all elderly patients felt that their dignity had been dishonored while receiving care.<sup>519</sup> Likewise, in many cases, other researchers have indicated that dignity is not being preserved yet.<sup>520,521</sup> Some researchers contend that culture has an important role in how dignity is interpreted and sustained.<sup>522</sup> In line with the finding of the Iranian study, researchers Matiti, Cotrel-Gibbons, and Teasdale articulate few important subjects that explain how patient dignity is influenced in healthcare settings. First, the unsuitable environment that referred to privacy-related issues, such as body exposure and the absence of private lavatory facilities.<sup>523</sup> As a matter of fact, the importance of physical environment in the safeguarding of dignity has also been highlighted in other research findings.<sup>524,525</sup> Moreover, extreme noise, deficiency of hygiene, and a shortage of amenities were also issues that relate to the physical environment. As per The Health Advisory Service 2000



in the UK, indicates that insufficient facilities and weaknesses in the physical environment and personal hygiene are necessary aspects of providing a dignified care to patients.<sup>526</sup>

The other finding is related to the communication problems that make patients feel undignified. All participants in the Iranian study specified the importance of good speaking or gestural communication. The results of the research disclosed that only a few patients were pleased with their verbal or nonverbal communication with health care providers, such as education or instructions on care. Most of the participants stressed that ineffective communication had not been an intention, but the outcome of a heavy workload on health care providers.<sup>527</sup> In addition, some patients faced unsuccessful communication due to language and culture barriers. This kind of result is also evident in the work of Jacobs et al.,<sup>528</sup> and Julliard et al.;<sup>529</sup> in some cases, even the way the healthcare team talked to the patients disturbed them. According to Marini, addressing patients without prior notice threatened their dignity.<sup>530</sup> Furthermore, in addition to workload stress, institutional shortages, such as meager salary, hazardous workplaces, and inadequate accountability for support of the nurses and physicians were documented as some of the issues affecting the practice of patients' rights.<sup>531</sup> As examples such as these show, patient dignity in healthcare settings is often devalued due to the lack of awareness and sensitivity about individual need. In addition, despite having a different culture, such as with the Iranian health care practice, patients still face problems that are similar to other countries. Nevertheless, more support and action are essential to increase the protection of patient dignity in the Islamic countries.

Research in Western countries has shown that preserving dignified patient care

involves safeguarding patients' privacy and respecting their autonomy.<sup>532,533,534,535,536</sup>

Dignified care also includes the patients' freedom to choose a treatment, telling patients the truth about their illness, emotional support, communicating with patients, maintaining their body image, and respecting their privacy.<sup>537,538,539</sup>

Respecting human rights and upholding dignity are also described as ethical goals of nursing care, regardless of patient's race, age, gender, faith, illness, or political, social and economic position.<sup>540</sup>

Overall, dignity is an important individual need; patients have the right to be cared for with dignity, and health care providers are accountable for providing dignified care to patients. According to nursing literature, health care providers have an obligation to protect patient dignity, because the lack of respect for dignity can lead to worsening the patient's health status. The benefits of protecting patient dignity are likely to include reducing patient stress, better confidence in medical practices, and fulfillment with health care environment; additionally, it could move on to better nursing care, reduced length of stay in hospitals, and improved patient outcomes. As a matter of fact, having regard for the patient's need to be protected from the unnecessary gaze of others was one aspect of the maintenance of patient dignity mentioned by nurses.<sup>541</sup> Nurses view respect for autonomy, privacy, control, advocacy and time as components of patient dignity. The features that patients accord to dignity include respect for autonomy, privacy, control, and choice of aspects of their care. Also, respect was shown to patients when they had their self-identity acknowledged, as well as their need for privacy and time. Privacy included saving the patient from the needless observation of others and preserving their confidentiality; for instance, avoiding others knowing that the patient had been incontinent.<sup>542</sup>

Vulnerable elderly people such as those with a disability, those at the end of their lives, and those with dementia are experiencing a greater lack of participation.<sup>543</sup> Elderly people do not always feel sufficiently involved in their care. They feel a lack of involvement due to ageist attitudes, the behavior of workers, and an absence of information, which often leads to inadequate and improper care for their needs. Treating the elderly, as individuals and involving them in their care are essential features of preserving dignity, even if the traditional customs delegate the authority of decision making to the family. Asking the elderly people how they would like to be addressed, what their needs and preferences are, and involving them in their care planning all contribute to the sense of being valued. With permission from the patient, personal space, for instance, could be entered with no loss of dignity.<sup>544</sup> The issue of individual hygiene can also infringe elderly people's dignity. Studies show that this subject has tremendous possibilities for humiliation and suffering to elderly people when they are frail, and not able to do things as they used to.<sup>545</sup> Moreover, limitations on care services can reduce individuals' options and wishes about how to be cared for, where and by whom, consequently, damaging their dignity.<sup>546</sup>

#### **4.2.2. The diminished principle of respect for autonomy and elderly health**

The bioethical challenges in the contemporary Islamic society have emanated from clashing lines of thought, offering diverse human interests and responses. Current bioethics that emerged from the West with a background of non-compliance with the church values had been founded on a materialistic perspective. Religion forms an integral part of the Islamic culture; thus Islam offers the model for thinking and making

meaningful decisions. As a contrary way of looking at the issue, Schultz and Levi declare that religion was merely a way of denying individuals the freedom to make their decisions.<sup>547</sup> Various arguments supporting the need for respecting autonomy concerning patients' care have been met with considerable criticism. For example, the end-of-life decisions, which are widely endorsed in the West, are highly refuted in most non-Western countries that believe in life after death. For Muslims, helping the elderly to attain good health care and avoiding death is an obligation of everyone in the society. The wellbeing of the aged population is viewed as a moral duty of the physicians and the society as well.

The caring for the elderly is considered an essential undertaking that should be prioritized while respecting one's autonomy. However, in some cases in which elderly patients wish to terminate their lives, physicians and members of the society are supposed to offer a motivating message. Such practices, however, infringe upon the wishes of the patient and thus compromise the principle of personal autonomy. Most of the elderly populations are vulnerable to terminal diseases, and treatment might not be sufficient to improve the situation. In some Western countries, the physicians are allowed to abide by the patient's wish to facilitate death. Contrary to that point of view, in Muslim law suicide or assisted death is not permitted. Since telling the truth is an ethical requirement, physicians are supposed to apply their knowledge when revealing an undesirable diagnosis to guard their patients against thinking of terminating their lives. In the Muslim society, advocating for something spiritual and enhancing social care is a way of diverting hard feelings. For example, the Code of Ethics of the Pakistan Medical and Dental Council (2001, sec. 7) states: "If secular Western bioethics can be described as

rights-based, with a strong emphasis on individual rights, Islamic bioethics is based on duties and obligations (e.g. to preserve life, seek treatment.)”<sup>548</sup>

Another example, in which the principle of respect for an individual’s autonomy is neglected in Islamic countries, concerns an elderly lady from Indonesia, who has a terminal illness and wishes for adequate pain relief at the end of her life. The patient had to tolerate suffering in silence because of her cultural and religious beliefs that she is obligated to comply with her husband’s wishes for not using morphine. Behind these misunderstandings regarding opioids were her husband’s own obligations to maintain hope and the belief that acceptance of morphine would be seen as a sign of surrender and a rejection of his wife. While her faith was important to her, she felt her physical condition required more attention and needed to express her concerns to the husband. Her hesitancy to use her individual autonomy was not only a sacrifice for her husband’s interest, but also a fear of the burden of treatment costs.<sup>549</sup> Thus, the expectation in this example for an autonomous action can be unrealistic even for the concept of respect for autonomy that embraces relevant cultural and societal beliefs.<sup>550,551,552</sup>

Part of the misunderstanding about the Islamic view toward the application of the ethical principle of respect for autonomy is that American legal and ethical values place a high priority on autonomy. The issue is self-governance; “being one’s person, without constraint either by another’s action or by psychological or physical limitations.”<sup>553</sup> From a religious standpoint, autonomy can be explained, in part, by reference to an individual’s community. As explained by Cook, meaning in life is determined by being part of a community.<sup>554</sup> Furthermore, the author declares that a community has values that transcend material and superficial unities. For example, the role of the church, as a

community within the commonwealth, is promoting the belief in the dignity of the individual. Cook states that the church must serve as a promoter for the infinite worth of individuals. Dignity and worth of individuals are intrinsic components of autonomy. Beauchamp and Walters argue that the principle of autonomy is commonly called the principle of respect for persons.<sup>555</sup> These authors limit their definition of autonomy to a historical link with respect. Furthermore, Thompson and Thompson point out that in the real world, few individuals have the power or the wealth for totally autonomous decision-making.<sup>556</sup>

In Muslim countries, social and family practices influence personal autonomy. The Western view holds such influence as primitive and inferior because personal opinions are, in most cases, accorded a subordinate role. Muslim culture perceives the family as a sociocultural entity that pursues both individual and familial autonomy. Family interventions are seen as a moral intervention from God; thus, the family cannot be excluded in the decision-making process regarding health care of the elderly. While Islam views the best ethical practices as those that consider family considerations in decision-making, researchers such as Sachedina believe that these family-based practices infringe upon personal autonomy.<sup>557</sup> Nevertheless, this view is found in the Islamic belief as unacceptable as autonomy. This argument is based on the understanding that very few aged people are competent to make autonomous decisions. A physician is justified in rejecting a patient's request for a diagnostic procedure if it is deemed harmful to the patient's well-being. In such situations, the family should assist the physicians in persuading patients from unwise choices and propose what they believe is meaningful for the patient.

Another way in which the losses of old people become humiliations is that the elderly decisions and responsibilities grow fewer and less significant over the years. That real loss of liability is aggravated by the responsibility that others feel they must take from them.<sup>558</sup> Moreover, some decisions are complicated and hard for even competent patients to make informed choices on their own. In cases in which a patient makes questionable wishes or he/she incapacitated to come up with an autonomous decision, then the family or the physician should be advised to respond to patient's preferred interests. Thus, when all stakeholders reach a mutual agreement of goals, recommendations should not be seen as interfering with the patient's autonomy.<sup>559</sup>

Nevertheless, if universal principles of bioethics exist, varieties happen in their interpretation and application, i.e., in the attempt to adapt them to local cultures and customs. This difficulty is similar to that which developed in the issue of human rights. Consequently, conflict with the values, attitudes, local customs, and religions are essential to establish the best measures with which to treat a patient.<sup>560</sup> Therefore, more consideration should be dedicated to these fundamental qualities in caring for the elderly patient. Moreover, it is worth noting how Muslim scholars, in dealing with the principles of bioethics, mainly refer to the classic ones that are shaped by Western scholars. While interesting, the principles developed on bioethics by Catholic bioethicists or thinkers from other religions, which could have a greater similarity with Islam, have been ignored. This oversight is possibly happening as Muslim experts only aim to use these texts solely as a starting point or a first formal approach, then to break immediately away from them to make room for the constitutional doctrine and the Muslim medical ethical tradition.<sup>561</sup>

Even though patients' rights are more frequently highlighted around the world, in Islamic countries, this is still a vague concept for health care providers and patients likewise. Despite several countries having prepared bills of patients' rights, study results from the European region of the World Health Organization (WHO) specifies that it is far more important to consider the usual conditions within the country in question than whether an approved patients' bills exists.<sup>562</sup> Respect for human beings is important in Iranian Islamic culture; however, the concept of patients' rights has not been considered until recently. The responsibility of patients' rights promotion is not explicitly acknowledged in the health care delivery system, and if some medical providers notice these rights, this change will be as a direct result of individual commitment rather than established rules and regulations. Furthermore, no non-governmental parties or consumer groups exist for observing patients' rights. Patients who face any unsuitable practice have no easy approach to mechanisms for pursuing compensational rights. Also, patients and their families usually lack information and, therefore, feel unsupported when facing physicians, other health care providers, and health institutions.<sup>563</sup>

In fact, the four principles of bioethics have yet to find balance with the Islamic principles (e.g., necessity, public benefit and justice). The essential difference that the principle of autonomy adopts in American and European culture when compared to any Muslim culture, especially when attached to tradition, cannot be rejected. In the former case, the importance given to the principle of autonomy starting from the hierarchy of the principles of bioethics is none other than the projection into the bioethical context of the importance of the liberal-individualistic matrix characterizing the juridical-political culture of the Western world, despite the strong differentiations within it. Vice versa, in



the Muslim context, primacy appears to be given to the principle of public benefit (maslaha), which takes superiority over that of the individual.<sup>564</sup> Although scholars emphasize the importance of participation and involvement in decisions for elderly people care, there are negative consequences of the current emphasis on autonomy; personal choice and freedom in both medical care ethics, and policy development. Three decades ago, Callahan warned that autonomy should be a moral good, not a moral obsession. It is a moral value, not the moral value.<sup>565</sup> Pullman also argues that an ethical framework based solely on considerations of autonomy assumes that the highest good is to maintain independence and that dependence is harmful. Such a focus results in an automatic failure for both frail older people and those caring for them.<sup>566</sup> While for the majority of the elderly who are not frail, the primacy of autonomy may be rightly placed, for many individuals, the reality is that physically and mentally, they will become more dependent, and caregivers must provide increasingly extensive care. Thus, when a value is placed solely on autonomy, caregivers need to consider the impact on the most severely dependent persons. An extreme emphasis on autonomy can lead such people to be viewed as minimal human beings requiring only minimal moral consideration.<sup>567,568</sup> Instead, people should acknowledge that the severely demented person, for instance, still has a fundamental moral worth regardless of whether or not that person is capable of exercising autonomy. Just existing as a human being confers a core value, which ought to demand humans' moral attention. When the dignity of frail older people is given center stage, this shift in perspective will not only protect all of their interests but also exert a moral force even though all autonomy and experience of personal dignity are lost.<sup>569</sup>

#### **4.2.3. The role of dignity and respect for autonomy versus family traditions: ethical decision making, and vulnerabilities.**

The concept of dignity is rooted in the Islamic religion, and it plays a great role in improving patient's self-actualization. Treating older patients with dignity helps enhance self-respect, empowers them to make choices, and encourages them to stay active. Older people feel honored and needed when they are treated with dignity. This feeling is essential since it triggers positive experiences and increases the urge to live. When old people are treated with dignity, they generate a view that they are being treated as adults and not children. Even though the Islamic society encourages assisting old people to make decisions, it does not essentially let them know the truth about their conditions. However, since it is their life, they should be allowed to know everything, and assisting them to come to a solution is necessary. Many experts believe that giving information about the disease and its cure, and involving the patient in the decision-making process are the main requirements to respecting a patient's autonomy.<sup>570</sup> According to the Islamic religion, life is hallowed; death is a universal fact and occurs only with God's approval.<sup>571</sup> This perception implies two findings: first, it is appropriate to involve actions to hinder early death; second, there are limits to hindering death.<sup>572</sup> The well-being of the dying individual is not just his/her own concern, but also the concern of the family and community. Therefore, patient treatment decision-making at the end of life should take into consideration the welfare of the family members and the community.<sup>573</sup> Despite that point of view, some Muslim researchers indicate that the four principles of biomedical ethics have been located in traditional Muslim societies;<sup>574</sup> others argue that the principle of autonomy is less applicable in deciding the medical treatment because patient welfare

is connected to the patient's family and social welfare. For Muslims, humans are residents and agents of their bodies that were generated by God.<sup>575</sup> Virtually, people do whatever they rationally can do to sustain health and well-being.<sup>576</sup>

Following Islamic teachings means that priorities are given to the family and that public needs override individual needs. As a matter of fact, in Muslim societies, as well as many other cultures, support for an aging person involves the whole family rather than the one individual.<sup>577</sup> Therefore, in Islam, a shared cultural belief is that a Muslim's special responsibility is to devotedly and well care for his/her parents in their old age.<sup>578,579</sup> Islam sets up certain values and principles for caring that have strong cultural and familial effects on family views and practices throughout Muslim cultures.<sup>580</sup> For instance, in Islam, "serving one's parents is a duty second only to prayer, and it is the parents' right to expect it. It is considered despicable to express any irritation when, through no fault of their own, the old become difficult."<sup>581</sup> In keeping with Islamic teaching, a human being is gifted with a body, abilities, and so on, and can only act in the way that God has approved. Thus, an individual cannot harm herself, such as through smoking, or using drugs or alcohol. In line with this, Islamic teaching encourages every health care provider to act as a caring individual for the patients and help them to abstain from any dangerous behavior and lifestyle that could endanger their health. This approach of the physician attitude is different from the Western type of autonomy; however, the customs are moving rapidly and, with the increase in education and development, the Western attitudes towards autonomy, privacy, and personal freedom are going to be more acceptable, especially to the younger generation.<sup>582</sup>

Furthermore, pain and illness are elements of life,<sup>583</sup> as is aging. According to Mehta, a human being must believe that aging is part of God's plan for humanity, a belief that acknowledges aging as the will of God and a time for removing some of past sins.<sup>584</sup> Some individuals imply that pain is a state of God's trial of individual's spirituality, which awakens the idea that "ultimately we belong, and will return to, God."<sup>585</sup> Additionally, Muslims believe that pain provides a chance to prove faith and trust in God's mercy, while some others imply that pain is a punishment for sin and an opportunity to start a moral behavior and inquire for God's forgiveness.<sup>586</sup> Therefore, health care providers need to have a deep understanding of the meaning of pain when dealing with an older Muslim patient, such as whether the patient's experience of pain is a spiritual one, or punishment, or some other experience.<sup>587</sup>

Societal discernments about the requirement for care, particularly on a continuous premise, seem to have procured evaluative essences, which reflect on both the beneficiary and the guardian. The thought of getting old may likewise bring about the requirement for care that seems to undermine the experience of dignity. Potential receivers of care dread being a burden and communicate disgrace at needing help or being dependent so that not requiring attention appears to have turned into a measure of individual dignity. This perspective of care is dominant in Western countries, as indicated by a study directed by Keith, et al., looking at American and Chinese communities. Elderly Americans wished that they did not become dependent; in contrast, the older Chinese wished that they had bringing up children who would take care of them.<sup>588</sup> Many elderly believe that their time on earth is not appreciated by the health care delivery system.

Informed patients know their obligations and expect their rights to be

accommodated. The notion of rights, however, is broad and needs to be supported through all parts of life. Knowledge and data bring power, and a scholarly community's attention to the issue of autonomy could provide the balance between patients and health care providers. The more that patients are aware of their health care rights, the greater the demand to have those rights observed, and the more knowledgeable health care provider considers that respecting and promoting for their patients is the proper thing to do. Additionally, study of the topic gives a proper environment in which to apply patients' rights. Therefore, knowledge and awareness can ultimately lead health care professionals to respect patients' rights.<sup>589</sup>

#### **4.2.4. Age and gender inequality in Islamic countries and the effect on the notions of dignity and respect for autonomy**

The traditional thinking about human beings presupposes that all people should be accorded the respect, dignity and right to make own decisions. The Universal Declaration of Human Rights echoes this segments by recommending that people be granted the freedom to make personal decisions.<sup>590</sup> However, these traditional conceptions of human dignity are disputed by the contemporary bioethics dilemmas, such as lesser questions on how the dignity and respect for the autonomy of a fetus or severely handicapped patients can be accorded.<sup>591</sup> Therefore, determining if humans of all ages should be accorded equal dignity and rights becomes a challenge. Many philosophers have challenged this viewpoint. In modern bioethics, Leners declares that a person is a rational agent able to make personal decisions, with a person defined as someone possessing qualities such as a sense of self-consciousness and rationality.<sup>592</sup> Nonetheless, it should be noted that people

at their youth age are not yet developed enough to make competent decisions, thus they should be directed in the process of decision-making. Similarly, elderly people are associated with aging disorders such as memory loss, agitation, and poor communication skills. For these individuals, the conception of personhood may not necessarily lead to self-control and autonomy.

Moreover, not all cultural practices share a common understanding of humanity. This aspect has an implication for the application of dignity and respect for autonomy across different genders. Women in the Islamic communities have struggled for gender equality and fundamental rights. Guido argues that patriarchy and religious traditions have colluded against the women around the Middle East.<sup>593</sup> Currently, across the Islamic community, women's rights are one of the most contentious issues in nursing practice. The development of women's dignity and respect for autonomy has not been smooth due to its collision with cultural and religious norms. The diminished place and the reduced status of the importance of women in the Islamic world have been reflected in clinical practice. In addition, women are denied the opportunity to participate in decision-making regarding their health. Also, their health care needs are not given enough attention when compared to their male counterparts who have the power to make personal decisions.

Addressing women's health issues is important in the public health setting, because of the disproportionate impact that they have on the health of the larger community. Women not only comprise 50 percent of the population, but they also bear a disproportionate share of health problems, primarily as a result of their childbearing role. In addition, women are mainly responsible for the health and well-being of their children. Women further provide most of the care for the old and disabled in communities.

Therefore, strategies that optimize the health of women and girls, particularly those emphasizing education, have been shown to improve the health of populations in developing countries dramatically.<sup>594</sup> It has long been known that gender is one of the major determinants of health conditions that will be experienced by individuals and communities. The reasons are not just biological factors, but also involve sociocultural, religious, political and economic factors. Sociocultural factors include value judgments made by families and societies regarding the relative worth and position of individuals, depending on their gender. These forces may result in the differential distribution of material and health resources based on gender. The disparity in literacy rates between men and women in Arab countries is only one of the most visible manifestations of this inequity.<sup>595</sup> In many Arab countries, the low numbers of decision-makers in health systems in which women may contribute is due to a lack of policies and programs that are uniformly suited to the needs of both genders. Whether arising primarily from society, culture or government, these factors impact health at many levels. These include whether individuals decide to seek healthcare for themselves or members of their family, the barriers that they may encounter in seeking care, the appropriateness, quality, and outcome of care that was obtained.<sup>596</sup> Many Arabs maintain strictly defined gender role differences and cultural values related to religion. Traditionally, men are the providers and are in charge of health, social, and political matters, while women are the child bearers and caretakers, in charge of household activities.<sup>597</sup> In the healthcare setting, the man of the family is often responsible for the final decisions, and for signing consent forms and surgical permits.<sup>598,599</sup>

As a matter of fact, women's health in general has been understudied. However,

only recently has the medical field begun to examine many of the subtle differences in health care needs between men and women, and considered many of the biological, social and cultural factors that affect both genders. When examining disparities between the genders, it is important to understand the social dynamics that affect gender and health in a contextual fashion. Researchers and practitioners should appreciate the complementary roles that men and women play in society, and how these roles impact the health of both sexes. In the Arab world, women's roles are rapidly changing in many areas, which creates both opportunities to improve health as well as dangers of exposure to new health hazards.<sup>600</sup> Although aging is a universal human experience, it would be inaccurate to ignore some of the biological and psychological differences between men and women during this time of life. As May indicates, "Women tend more often than men to associate aging and death with the corruption of bodily form."<sup>601</sup>

In concise, the change in traditional familial structures poses a threat to elderly women security in later life. In general, elderly women are unaware of their health rights and have been dependent on their family to decide what is best for them regarding their health. Yet, the Islamic Sharia law supports women's health rights, however, there is a misunderstanding in the culture. For example in Saudi Arabia many women still need to obtain permission from their legal guardian before they can obtain medical care, sign for treatment and surgery or even have access to health care facilities. In fact, Sharia law and the rules of Ministry of Health in Saudi affirmed that women have the right to make decisions and sign for themselves.<sup>602</sup> But unfortunately, some physicians do not recognize the right of women to consent for treatment; out of fear of encountering problems with male guardians.<sup>603</sup> The issue is that there is a tremendous need for



changing the Islamic traditional interpretations to achieve an agreement in a religiously oriented society; empowering and educating women and health care providers on the ethical principles of respect for autonomy and human dignity are needed for the well-being of women.

#### **4.3. Cultural differences; Islamic culture versus Western culture**

The word “culture” refers to people’s beliefs, traditions, practices and social conduct. Thus, people’s cultural viewpoints, such as their views on health, disease and medical treatment are affecting all aspects of life. For example, a contemporary report revealed that elderly people have some nonmedical descriptions of what health means to them. In these instances, health could mean physical activity and functioning, enjoying work, and being active. Other individuals may see health in a whole different way, such as the absence of illness or as the presence of physical protection.<sup>604</sup> Furthermore, cultures are not just limited parts such as the Arabs, Indians, or the Japanese. In fact, individual units in society, for example, the health care profession, can promote their particular culture, which can affect the communications between medical professions and patients. Thus, culture is a dynamic process; individuals adjust to modifications in their surroundings, for instance, moving from a rural to an urban area, or getting an education. Occasionally, transformations of immediate surroundings leave behind the cultural ability to adapt such changes, which could generate conflicts among societies and their surroundings. Therefore, to deliver quality medical care, understanding the culture of patients, healthcare providers, and the medical system is important. Family role in the person’s health varies between cultures. Understanding culture is central as it sways the

way people create, accept, and understand information; and it affects how people recognize and express pain and suffering.<sup>605</sup>

Sharing information is a cultural issue that was found among Muslim elderly patients. This issue is the reason responsible for the unwillingness of the elderly patient to discuss family problems with outsiders. One of the reasons behind this reluctance is to avoid increasing the burden of medical care and costs for their family. This matter is relevant to the Arab culture; first, elderly people believe that it will make them less respectful for their family members when discussing personal or family issues with an outsider including health care providers, and second, most of the elderly are economically dependent on their family.<sup>606</sup> It is well-known that the Quran advises younger people to respect and care for their elderly. According to Bengtson, et al., the old in the East are still revered and protected.<sup>607</sup> However, in reality, the Muslim family performs a significant role in medical decisions, and the elderly patient has to listen to the judgment of his close family regarding the treatment he/she is going to receive. Thus, the Western attitude of independence is not acknowledged in many Islamic societies. Meenan, Rees, et al., argue that the current approach of respect for elderly people in Islamic countries is not secured, because of a lack of legal protection for older persons. In fact, elderly people in Islamic countries are not completely protected by international human rights systems. Most of the Arabic Middle Eastern nations fail to apply enforcement laws that identify the Islamic duties and obligations that their citizens are already supposed to be following.<sup>608</sup>

Furthermore, in Asia, Africa, and the Middle Eastern countries, no public health insurance exists. Thus, the family takes on the burden of any medical expense. An elderly

individual may often endure pain and keep silent instead of asking a family member to take her to a hospital because she feels she is already a burden to the family. The Elderly feel that their role in the family is to be respected, and health care providers have to understand that Islamic cultures, like many others, do not give importance to autonomy as is expected in the West.<sup>609</sup> Beauchamp and Childress support the patients' right to decide on whatever they find appropriate. They can assign the decision-making to a family member, or a proxy. In fact, there is an important obligation to safeguard patients' right to choose, as well as the right to consent or decline any medical treatment.<sup>610</sup> Thus, a health provider is obligated to clarify all the information and possibilities of treatment, and leave the final decision to the competent adult patient or guardian, when a patient is incompetent. Islamic regions should improve the Islamic legal standards and the traditional models concerning elderly people's care and protection. Older people need to feel that they are valued as human beings, and their health care decisions should be respected, even though the family members plays a significant role in their care planning, showing elderly citizens that dignified care can promote their well-being. Thus, these challenges can be stimulated by social awareness of the needs of aging persons. In the same manner, and as the elder population grows, many cultural practices have developed and performed an important role in this area, like some cultural practices show that there is no easy way to change without irritating the culture and teachings of that community.<sup>611</sup>

Another cultural factor involves the issue of sensitivity. The older people's perception of themselves depends on their ability to cope with and manage their aging.<sup>612</sup> Elderly people who see their elderliness positively will insist on their continuing role and

effectiveness in their families and societies. By contrast, old people may perceive their elderliness negatively, especially when they lose their role and status in both the family and society.<sup>613</sup> Similarly, the elderly may be seen positively or negatively by the younger generation. For instance, a teenager views his incapacitated old father as the prime authority figure in his life. While other younger generation may see the elderly as old-fashioned and a burden.

In general, culture has a significant position in how dignity is understood and maintained. People gain values, such as respect, privacy, and how to be addressed; they set criteria according to these values, and from these criteria evaluate what is suitable. For instance, eye contact used as a way of communication can vary between cultures. In Western culture, eye contact is necessary to show that the individual is giving attention to the other person. Nonetheless, in Muslim cultures and many others, eye contact is avoided when communicating with a person who occupies a higher position in the family or society in general. Thus, a person will develop a feeling of self-respect; honored and valued when these criteria are met. However, if these criteria are not met, then the sense of self-respect will decrease, and the person's feeling of pride will be diminished. For these reasons, people have a belief about how they wish their dignity to be maintained.<sup>614</sup> In addition, patients may show different responses when their dignity is threatened. They might be shamed and express their feeling through anger and violent reaction, or in some cases apologize due to their sense of embarrassment. According to Solie, elderly people have a strategy that is different from the younger people. Notably, old people need some control over their lives and do not want to be forgotten.<sup>615</sup> However, regarding control, elderly people encounter problems that younger people do not encounter. These problems

include losing physical mobility, making decisions about whether to move into an extended family or nursing care, and dealing with problems associated with wellbeing and end of life. On the other hand, being remembered and not forgotten can include leaving an inheritance for the next generations.<sup>616</sup> Furthermore, Solie argues that, in later life, the idea of control is universal because older people face numerous losses, such as physical function, peers, identity, home, and financial independence. He further argues that experiencing several losses can increase the possibility of an adverse interaction between older people and others,<sup>617</sup> meaning that their adverse reaction is a way that some elders use to exercise control. Hence, holding back a bit and allowing the elder person to show control would be a good way of dealing with this kind of reaction.<sup>618</sup> In brief, when a person's dignity is in the hands of others, defiant self-respect is an exception, at times an aberration. Older persons expect to be in control of themselves and many of their situations, but with an illness, such power will be weakened. Therefore, sensitivity to the patient whether through verbal or non-verbal communication is needed to maintain self-esteem and control, hence maintaining dignity. It is important to keep in mind that an individual's feeling of loss of self-control is painful.<sup>619</sup>

Other issues arising with elderly care concern isolation and privacy. Numerous healthcare facilities might be culturally insensitive to privacy issues. Since the Muslim belief stresses modesty, many elderly women prefer to be attended by female health care workers, and the same way around for men. They like to have health services from people of the same gender, especially when they need to be showered and dressed. In effect, Islamic health care forms a structure by which people select a physician or service provider. Despite the fact that this might be different among Muslims, in wellbeing or

social services, preference is regularly given first to the Muslim doctor of the same gender, next to a non- Muslim of the same gender, then a Muslim physician of the opposite gender, and finally, a non-Muslim of the opposite gender, respectively.<sup>620</sup>

Furthermore, in some cultures, attitudes can negatively affect general health. For instance, in some societies, going out for women is limited and discouraged; however, in a small city, this kind of restriction and isolation can cause the feeling of dissatisfaction with life, fear, absence of activities and obesity in several cases. In these instances, additional social practices can positively influence wellbeing. For instance, family care and help can support individual health status and reduce many physical and psychological stresses. For many elderly people, religious practices and beliefs offer a feeling of safety, self-respect, and well-being. Moreover, in Egypt, a sociological study of medical doctors found out that physicians addressed culture as the first reason hindering the appropriate provision of health care. Frequently, they suggested that people who live in villages or sick patients were ignorant, and this ignorance blocked the delivery of proper healthcare and treatment. However, ignorance reflects the unrecognized disagreement between the health care professional's medical and personal values and those of the patient.<sup>621</sup>

For example, an older woman who lives in a rural area has a cataract and cannot see well. She goes to a public eye hospital to get eye drops. The optometrist tells her that she needs surgery, but she firmly refuses, saying that God is the only Healer, and she is very old for this sort of technique. Thus, the optometrist moves on to the next patient, saying that it is useless to manage older people from rural areas, especially women, because of their ignorance. In clarifying the case, the woman here has reacted contrarily to the term “surgery” because she has heard numerous stories of people enduring some

complications and having bad restorative treatment after surgery. Therefore, she refuses to be hospitalized, fearing that the staff will treat her poorly. She is also anxious about the risk of the procedure for her age and would not like to die in the hospital. As can be seen from this example, the physician appears to be uncaring about her worries. Under these circumstances, prior negative encounters with treatment are the reason preventing the patient from obtaining the care and not ignorance. Adverse events with medical procedures cast widely in close societies. Individuals know one another well, and the torment of one person from the group can be quickly conveyed. In fact, the physician could assure the woman and her family that better health would help her and the whole family and society. By evoking the silent fears and the way applicable data is conveyed, the doctor could help this patient and her family to consider the advantages and disadvantages in her situation.<sup>622</sup> In the light of this example, the study of behaviors, social life, attitudes of patients and societies becomes almost as important as studying the biological aspects of a disease. When health care workers know their patients' values, social surroundings, and living situations, they can often deliver better treatment and results. Unfortunately, minimum effort on this aspect of medicine has been made in the Arab world.<sup>623</sup> In many Western countries, the essential focus in clinical practice is on the patient's independence or self-rule. But, in Islamic societies, people incline toward a more family-focused approach to deal with choice making.

A person who discusses other imperative life choices with the family, for example, a job or education career, the names of his offspring, would likely favor trusting his family to share the burden of deciding on critical medical choices amid times of emergency. The family regularly does not want their relative patient to know about the

poor diagnosis. This position somewhat reflects faith about the force of hope and the negative results in the person of losing faith. The family believes that this approach would help to strengthen the patient's faith and assist him to recover.<sup>624</sup> The culture in Middle-Eastern countries guarantees respect for the elderly and highly appreciates the popular connections of closeness between all individuals of the family. The eldest person is an essence of spiritual blessing, religious commitment, wisdom, and affection. In spite of the general feeling among the vast majority in the area that moving an elderly parent to a nursing home infringes upon their religious feeling of obligation toward them,<sup>625</sup> numerous families are confronted with circumstances in which they have no other option. It is clear that many elderly persons in nursing and psychiatric institutions are there due to circumstances with which their families are unable to cope, including the families living abroad, their inability to support their elders financially, and the nature of the diseases from which the elderly suffer and require professional care. Although rates of institutionalization of older adults are lower in the Arab world than in Western nations, institutionalized adults tend to be far more dependent and in need of specialized care than do nursing home patients in developed countries.<sup>626,627</sup> This pattern will continue to worsen as morbidity patterns change, leading to longer life spans with chronic illness, reliance and loss of self-sufficiency for increasing populations of elderly in the area. Older individuals in the Islamic countries obtain much social and financial care from family, mainly from the next of kin. With smaller families being the pattern, fewer potentially supportive children will be available to care for the elderly. According to research in developed countries the majority of those capable of supporting their aged parents are doing so. Nevertheless, general trends of family obligations are likely to be



diminishing with the increase of financial burdens. Furthermore, young residents may become more concerned with the future of their children than with the challenges of their parents. In addition, women, who have customarily played significant roles in providing family care, are increasingly entering the work industry for personal value, career, and financial need, and are no longer able to care for aged families.<sup>628</sup>

According to Callahan, one of the current myths is that having dependent elderly people in an organization for a permanent residency relieves all concerned of the stress and necessity of caring for the person. But our parents still remain our parents, waiting for our love and affection even if they are in an institution, and probably even more so. Recent American studies have confirmed that children and spouses continue caring for their institutionalized elderly, and they spend a great deal of time doing so. Family caregiving has an irreplaceable role in caring for the dependent old.<sup>629</sup> Caregiving, however, should be an act of free choice and personal commitment of both the caregiver and the care recipient, not their duty when outside help and alternative forms of care are not available. Only then can the dependent elderly preserve their dignity and freedom and find in the family the place where they belong.

#### **4.3.1. Physician-patient relationship in Islamic countries**

Van Bommel declares, “Muslims feel very strong that it is God who does the actual healing, the doctor being only the agent for the will of God.”<sup>630</sup> He further states: “For a Muslim patient, absolute autonomy is very rare, there will be a feeling of responsibility towards God, and he or she lives in social coherence, in which influences of the relatives play their roles.”<sup>631</sup> Thus, individual choices are accepted only if they are

the right ones. Furthermore, the patient's right to know the truth about her medical condition is highly supported in Western medical practice. But Islamic interpretation of this right has a different emphasis. The physician is responsible for ensuring a peaceful life for the patient; therefore, if in her judgment, the knowledge about the terminal and the non-contagious disease would be counterproductive, then withholding the truth from the patient would not be sinful, even if the patient wishes to be fully informed. The management of suffering and death produces tensions for the Islamic practitioner. A Muslim patient believes that suffering is a test from God, presenting an opportunity to show courage and faith. The Islamic position on euthanasia is very clear; life cannot be terminated either actively or passively because that interferes with God's will. Thus, continuing aggressive therapy is frequently requested.<sup>632</sup>

In Pakistan, for instance, the family's roles in decision-making processes are well acknowledged by many physicians. A study conducted in Pakistan regarding physicians' perceptions of informing patients of their health status found out that several numbers of physicians reject any differences between the patient and the family. These physicians believe that the patient and family should be addressed as one unit and should not be separated. According to the physicians in Pakistan, patients and their families are one and the same, reflecting the Islamic idea on the matter; therefore, there should be no difference. Many physicians indicate that patient diagnosis is being addressed to the family members first, before approaching the patient, especially when the diagnosis is related to a life-threatening disease.<sup>633</sup>

In health care settings, some elderly people are dependent on their children. Parents in most situations are responsible for most of the decision-making for the long-

term care of the patient. As a matter of fact, in Islamic countries, health practice may negatively affect the family situation. As an illustration, the family member would be affected by the health care decisions that require a responsibility of care, emotional stress, or high costs. Therefore, communication is necessary for health care workers, patient, and family. At the same time, health care providers should be attentive to the different kinds of self-perception and should select the best option of actions for the situations.<sup>634</sup> In home health care, the power shifts toward the patient. Unlike in hospital where the physician place orders to be followed by the facility workers. Thus, in home health care there is no restricted agreement that all of a doctor's orders will be followed. Moreover, care for a terminally ill patient is delivered at home, and it tends to be difficult to apply all required procedures due to a lack of resources and proficiency. Agencies such as hospice assist in providing home care to those individuals who need end-of-life care. The organizations that help in providing care and facing decisions about death should assist in eliminating ethical dilemmas by proper planning and communications with?. For instance, an older patient who has been diagnosed with slight dementia has fallen and has hip pain; the patient resists going to the hospital despite the support of health care providers and family. The authority of surrogate decision makers may be less required in the home care context if the caregiver appears to act for the best interests of the patient. In the light of this situation, the ethical principle of beneficence obligates that the physician considers relieving the patient's suffering and future disability.<sup>635</sup> In spite of that dictum, patients in the hospitals are likely to be more vulnerable because of acute medical challenges; nursing homes residents, in contrast, are usually confronting chronic medical difficulties.

Institutionally, it is observed that health care workers communicate with elderly patients following their social perception of older persons and the institutional power the workers acquire. It has been reported that many healthcare providers in hospitals and nursing homes perceive their elderly clients as frail and needy, a perception that consequently reflects increasing incidences of mistreatment of older residents.<sup>636,637</sup>

In the nursing home, doctors are required to give careful consideration to the parity of autonomy versus beneficence in a few settings: at the point when administering to occupants with small choice-making limit, when surrogates are settling on the choices, and when nurturing inhabitants at the end of life. Elderly individuals who live in nursing homes might have significant physical hindrances so that they are not ready to inhabit homes without great personal and mechanical help. They may undergo cognitive impairment that makes them unable to live independently. They might endure intellectual debilitation such that they would not have the capacity to live autonomously. These conditions make them exceptionally vulnerable, and the real beneficence inspired by this vulnerability ought to be evaluated against the inhabitant's self-sufficiency or respect for the individual when choices are made.<sup>638</sup>

Some elderly people perceive health care providers and institutions positively as helping them to cope with, recover and overcome diseases and symptoms associated with age. Hence, organizations and communities dealing with the elderly are very concerned about the quality of health services provided to their members. However, some elderly may perceive institutions as isolated places from their family and community, and they are prone to be mistreated and abused due to their vulnerability and weaknesses. Recent reports on elderly residents of hospitals and nursing homes suggest that having home-

based care and family care seems to be more favorable and beneficial to the elderly than health institutions.<sup>639,640</sup>

Moreover, many elderly people feel that availabilities of the necessary services are important for them to feel that their rights are being respected. The staff behavior is a vital element of dignified care. Showing the significance and value placed on older individuals will promote trust and boost both the dignity of the person and that of the staff. Furthermore, good manners and a readiness to listen are qualities that the elderly appreciate in health care professionals. Protecting confidentiality, requesting informed consent to do examinations and give data, sensitivity to physical and eye contact are additionally essential in respecting patient dignity. Also, utilizing first names as is usually done was seen as an indication of lack of compliance and improper in the health practice. Most elderly people believe that the utilization of first names means a cozy relationship, which they did not have with the majority of health care workers. Albeit a few elderly members who were in long-term care favored being called by their first names, a reality which appears to strengthen the importance of the relationship in that environment. Information about the favored method to address them is a way of showing respect, instead of expecting that individuals would not mind how they are referred to.

Undignified care underscores the vulnerability of elderly people regularly by stressing the imbalanced power relations between health care providers, particularly physicians, and patients. Old people feel especially powerless in such circumstances because of their hesitance to grumble, inspired by a paranoid fear of unjust and inadequate care. One of the highly significant ways in which such weaknesses are increased is either through an absence of participation in decision making regarding the

care, or in the way that elderly people are forced, or induced, to take whatever health care providers recommend as the best option for care. This concern was especially apparent when treatment included new technologies, and at the end of life.<sup>641</sup> According to Tadd's study examining older individuals and their family's views of dignified care and health care providers' behaviors in relation to dignified care, professional participants recognize numerous obstacles to dignified care, for example, staff shortages, financial and material resources, attitudes to routine, and the absence of direction on supporting dignity. Just a few of health professionals had the chance to discuss dignity and dignified care during their educational training.<sup>642</sup> It is additionally clear that, for many elderly individuals, particularly the vulnerable and weak, their dignity and human rights seems, by all accounts, to be disregarded on an every day and methodical premise. By and large, this result is the aftereffect of overwhelmed health professionals attempting to adapt to unreasonable workloads, at times in negligent and selfish ways. Instead of being a useless idea, which means no more than respect for individuals' autonomy,<sup>643</sup> dignity seems, by all accounts, to be a rich and solid concept. In spite of the fact that respect for autonomy and dignity highlighted profoundly in participants' records, dignity likewise involved different ideas, which are especially pertinent to the care of elderly individuals, including respect for autonomy, the meaning of responsibility, fairness, acknowledgment and personal identity, and respect for self-governance.<sup>644</sup>

In health care practice, sometimes it is hard to make a decision for the patient's care. Hence, a doctor on occasion needs to choose for his/her patient in consideration of accessible information, his/her experience, companions, and agreement of the group. Recognition of people as being worthy of respect as opposed to being inefficient and a

burden on resources is plainly essential; however, acknowledgment of individual worth is additionally shown in the way in which health care providers communicate with elderly individuals. Old people needed to be appreciated for what they have accomplished in their lives, and the role and commitment they have made to family and society. Also, for health care professionals, society's acknowledgment of their exceptional abilities is vital. Affirmation of independence is a critical part of the dignity and respect of individual autonomy. Being seen as somebody with a history and associations, someone who has been where their caregivers are today, is additionally essential. This idea suggests being dealt with in ways that are thoughtful to elderly personal history is fundamental to be treated with dignity.<sup>645</sup>

According to an extended constitutional and cultural practice in the United States and other Western countries, care should be delivered in a manner that respects the patients' dignity and autonomy,<sup>646</sup> and this approach is in agreement with patients' desires. Numerous researchers have acknowledged that what patients need from health care is to get help, alleviate pain, and to minimize the burden on families, intimate connections with family members, daily activities, and a feeling of self-sufficiency.<sup>647</sup> As a matter of fact, health care providers attend to focus on working with the consequences of people's weakness and barely on their strengths and desires. The difference between what the patients need and what is being provided is apparently seen through the weak understanding and management of the health care professional's goals and the elderly patients and their families.<sup>648</sup> Furthermore, the importance of recognizing patient dignity has been realized in recent years. Even though dignity is a fundamental part of medicine, it is a controversial concept that affects health care practice.

#### **4.3.2. The problems of families and tradition when caring for elderly people**

While the requirement for long-term care and guardian decision makers seems, by all accounts, to be expanding, the availability of accessible caregivers appears to be decreasing; for example, family structure is getting smaller, which lead to unavailability of the family members to care for elderly parents. Increased family instability and more significant geographic movement imply much of the time that fewer caregivers are eager or accessible to care. In the past, caregivers used to be women who did not work outside the home; today the caregivers are still women, but they work outside the home and are also obligated to care for their children. In the meantime, lack of professional caregivers, geriatricians, and nurses is hurting the situation. In fact, a nurse frequently lacks the advantage of compensation and benefits that may interest a lot of personnel in the job, which is an issue that is demanding critical consideration.<sup>649</sup>

Thus, the increasing access of women in the workforce and the need for financial support have made it harder for women to be totally responsible for taking care of their elderly parents as they had done in the past. In spite of the fact that the development of women's career has been received as an important step for their freedom and fairness, it has changed society's views about the difficulties and sacrifices in different features of life such as in caregiving functions and obligations.<sup>650</sup> In a study on the essential value and custom of mutuality, Mercier, et al., found that the more grounded the relationship quality between a mother or a father and daughter, the more the feeling of familial and loving duties daughters felt about giving care to their elderly parents.<sup>651</sup> However, the aftereffect of such feelings and endeavors to keep caretaking might well be burnout,



particularly if the family caregiver is taking care of an elderly individual with a complicated sickness, incapacity, or a memory loss who needs continuous care.<sup>652</sup> Given the ongoing effect of Islamic values in the lives of Muslim people, in many cases, the only available solution of care for elderly with chronic sicknesses, physical, or mental disabilities is for the adult children to move in with the elderly or the other way around.<sup>653</sup>

In Muslim communities, many people are raised to consider the family unit as a continual source of support. Extended family members may be highly valued as well. They may be expected to be involved and may be consulted in times of crisis. As pointed out by Meleis and La Fever, although Muslim Arab people may “value privacy and guard it vehemently... their personal privacy within the family is virtually nonexistent. Decisions regarding health care are made by the family group and are not the responsibility of the individual.”<sup>654</sup> In some cases, when a person is in distress, the family may intervene on behalf of the identified client and may try to control the situation. Health care providers determine the dominant relationships within the family, and they collaborate with the family members on behalf of the patient.<sup>655</sup>

Moreover, Al-Kernawi and Graham claim that a family unit in Muslim Arab societies has been viewed as a constant wellspring of support, and the relatives might be included and consulted whenever a family member is in need.<sup>656</sup> The custom of blood retribution among the Muslim Arab societies can be another cause of familial and tribal solidarity and relationship. On the off chance that a family or tribe member had committed manslaughter, alternate individuals from those social units will be entirely and indeed responsible for this act, and vengeance is required for them and from the

exterminator.<sup>657</sup> Furthermore, it is still the father of the family who has the authority to decide what?, even on the personal matters of his children or matured adults. In several situations, disrespecting the father power by any member of the family is considered as disobedience, and such an individual would not get any support from the family or other relatives. Disobedient mature children are disregarded and neglected in their society.

A less critical yet evident comment among elderly people in Malaysia was the acknowledgment that old age implied freedom from obligations. These obligations referred to, for example, parenting duties, household jobs, and earning money for a living. As in Singapore, 80 percent of elderly people live with their children.<sup>658</sup> As a result, the older generation has progressively passed the family obligations to their children, while they contribute by assisting according to their physical and financial ability. In general, the main reasons for stress and worry in old age emerge from the absence of funds, health problems and disease, and loneliness. Other reasons might be for example, matters that are connected with sorrow over the past life experience, or depression following the death of a life partner or a forced change in living arrangement, e.g., institutionalization. In dealing with these issues, elderly people need to open their private means and also social support schemes, for example, relatives, and group resources. Inner resources incorporate individual methods for dealing with spiritual nourishment, which are connected with religious convictions.<sup>659</sup>

In general, elderly persons usually prefer to live in their own homes. McAuley and Blieszner found that elderly people's least preferred living arrangement was moving into the home of a child or other relative.<sup>660</sup> When the need for assistance becomes significant, however, it is often necessary for the elder and the caregivers to reside in the

same home. Furthermore, family and work obligations often conflict with caregiving responsibilities. Studies of the experience of providing assistance to dependent elderly persons have demonstrated that caregiving has an intense impact on the caregiver's lifestyle. The most severe infringement on the caregiver's lifestyle is confinement.<sup>661,662</sup> Caregiving also affects the relationship between the caregiver and the care recipient.<sup>663,664,665</sup> As stated earlier, families turn to formal services only after informal supports are deemed inadequate or exhausted, and usually because of necessity, not personal preference. Although home health care services can be either empowering or disabling to the patient and caregiver, reimbursement for care is based on individual needs, rather than family needs.<sup>666</sup> Nevertheless, a sequence of relating factors causes pressure for Muslim families who try to implement this approach. First, as family members move to a different city or country looking for education or work, the traditional extended family becomes over-extended, and elderly individuals become isolated. Second, as women pursue professions that are not available in their town or country, they cannot spend a lot of their time in the home caring for others. While this handicap can lead to the feeling of guilt, their commitment to their religious beliefs and cultural traditions means that they must find a way to deal with the situation.<sup>667</sup> In Islamic culture, parents care for their children when they are young, and via a sense of reciprocity, adult children care for their parents when parents are old.<sup>668</sup> Similarly, Al-Heeti indicates, "parents sacrifice so much for their children when they are small; a Muslim child is happy to return that sacrifice when his or her parents can no longer care for themselves. It is not a burden but a means of winning a great reward in Paradise."<sup>669</sup>

The cultural backgrounds of Muslims and the teaching of Islam's philosophers

discourage Muslims people from placing their elderly relatives in nursing homes.<sup>670</sup>

Clemetson argues that the religious belief comes at a price, as medical insurance provides funds to cover nursing home for various family and aging people; still these programs do not provide the equivalent level of aid to individuals who live with family members at home, or at least not to all families who need upkeep and care.<sup>671</sup> The Quranic provisions openly give directions to care for elderly parents. The Sunnah traditions emphasize children's duty to care for parents, as they were cared for as infants.<sup>672</sup> Traditionally, families and religious leaders have interpreted this guidance as a duty to care for parents at home.<sup>673</sup> Subsequently, for many younger adults and relatives, the thought of elderly parents or relatives being in a nursing home is intolerable and is seen as disrespectful to the Qur'an.<sup>674</sup>

With the changing demands of life, many families are being compelled to break the customs of Muslim culture and adjust to Westernized practices of elderly care. Besides the influence of changes that emerges out of medical need, Muslims should likewise understand the objective reality that their elderly parents might need continuous and extraordinary care outside of the home.<sup>675</sup> Even though a person's disease or incapacity is seen as God's will, it is likewise God's will that families do their best to assist those with wellbeing conditions, and at times, this implies going to outside services.<sup>676</sup> Given the profound anxiety and guilt that most average Western families feel because they choose to place their ill or poor parents in an organization, it is similar that some Muslims see institutional arrangement for elderly people as a form of neglect and rejection.<sup>677</sup>

#### **4.3.2.1. Dependency and vulnerabilities**

Autonomy is a formative notion on which Western culture and health care delivery is largely based. Indeed, it has become the foundational principle of health care. Such a preoccupation with autonomy obscures the fact that individuals ultimately lack control over aging, illness, disability, suffering, and death. To admit this lack of autonomy is to admit that the human condition is beyond human control; to relinquish autonomy is acknowledging the individuals' profound vulnerability, especially as they age. Furthermore, this preoccupation with autonomy relates to independence, since a person's independence and his/her ability to live independently of others is symbolic of his/her autonomy. Within the United States, dependence has been strongly associated with weakness, incapacity, neediness, and a lack of dignity; insofar as individuals can resist dependency, they can maintain their dignity and self-respect. But this strong emphasis on autonomy as independence has had a very negative impact on aging and aged persons, who find themselves increasingly in need of assistance to bathe, go to the bathroom, dress, eat, and get around. People find it shameful and embarrassing to admit that they can no longer perform all these tasks unassisted, and as a result, many older adults will refuse for as long as possible to ask for help; instead, they struggle or simply go without their baths or meals rather than ask for assistance. Focusing primarily on autonomy as making self-directed choices is an impoverished view of human being moral obligations to elders in this situation. Therefore, quotidian acts like bathing, dressing, etc., compounded by history, a foreshortened future, loss, and the necessity for trust, in addition, mutuality must be included in the study of ethics and aging.

Ethics is inscribed in every facet of daily living. When faced with the need to make decisions, sensitivity, flexibility, discretion, and improvisation to find precisely what responds to the very particular case are called for. Attention to the histories of relationships and the understandings unique to these accounts are needed to determine what responses between these particular people mean.<sup>678</sup> The moral status of others as caregivers and the elder's need for a simple identity that grounds self-respect and self-esteem calls for an enlarged concept of what is morally valuable in long-term care. To neglect other important features of the moral life can reduce individuals' choices and the support of well-being. Thus, what matters is not only not to oppose making decisions, sanction paternalistic interventions, or insist that individuals can function only within a set of commonly endorsed background conditions, as many communitarian thinkers would hold, but the moral poverty that a singular emphasis on the language of autonomy suggests is what matters. Individual choice is not the necessary condition for self-respect. In fact, writing an advance directive or giving informed consent is a fragment of what it takes to know the individual's dignity is respected.<sup>679</sup>

Whether because of physical or mental impairment, dependence is viewed as being utterly humiliating, and many elderly people express a fear of becoming a burden on their families, as they find this prospect shameful. They also acknowledge that there are degrees of dependence that affect a person's experience of dignity. When disability or frailty is such that intimate care would be necessary for the rest of one's life, then dignity is difficult to maintain. For this reason, the attitude of older people towards increasing dependence and infirmity is essential. If people remain confident regardless of their disability, then they can do better in retaining their dignity.<sup>680</sup>

#### **4.3.2.2. Language barriers**

Effective communication is essential for respecting patients' dignity and autonomy. In a bid to offer quality care, good communication should be facilitated between older patients and health care providers. Effective communication skills mark the process entailed in assessment and care provision for the older people. Since communication relies upon a common language, this pre-requisite may not be present in many elderly patients. Due to the high rate of globalization, the medical sector has been dominated by the mobility of labor and trade goods. This aspect means that caregivers in most of the care centers in Islamic nations might not necessarily be familiar with the local language. Besides, language proficiency among the aged people might be influenced by age-related disorders such as memory loss and psychiatric conditions. Limited ability in English is an important communication barrier in Islamic societies. The elderly people are less likely to be proficient in English since it is a second language that has gained access to the Islamic world in recent years. For instance, most health care providers in Saudi Arabia are from nations such as the United States, the United Kingdom, and other countries with different cultural backgrounds. A language barrier can also arise when a sender speaks too quickly for the receiver to comprehend. Additionally, providing too many details or addressing the individual harshly can result in a language barrier. Furthermore, using a commanding tone can destroy a patient's self-esteem and cause communication failure. According to Fry, Veatch, and Taylor, the aged are very vulnerable to demeaning emotional tone and a body language that does not support a positive implication.<sup>681</sup> Cognitive and physical impairments can damage several elements

of communication, and great care should be considered to ensure that language proficiency is accounted for by any exchange.

Stereotypes also affect the way caregivers communicate with elderly patients. The stereotyped sentiments that are socially attached to people relating to their age and health status can cause health providers to act dismissively when dealing with aged individuals. Besides, the lack of awareness about certain stereotypes can create a damaging impression. Non-verbal communication such as gestures, body language, eye contact, or facial expressions often transmits messages before a person speaks. For this reason, it is desirable for care providers to develop awareness of their body language since they can pass a wrong message. In addition, it is argued that caregivers with a small comprehension of elderly people's social activity would be expected to use baby talk to communicate with the old.<sup>682</sup> According to Caporael, elderly residents with low functional ability scores prefer being addressed with baby talk.<sup>683</sup> Nonetheless, it could be argued that caregiver's adoption of baby talk for interacting with older people might be influenced by their stereotypical perception of the elderly.<sup>684</sup> Thus, the communication environment is a critical factor while handling aged patients. Most of the geriatric care systems in the Islamic countries are yet to be fully developed compared to the Western countries.<sup>685</sup> The level of development is still small, and funding for health resources is difficult. This aspect implies that residential aged care resources and hospitals are always active zones, and thus the chance to converse quietly and privately may be unrealistic. This situation places aged people at a disadvantage since they are controlled in their conversation. Regardless, the Islamic traditions expect the service provider to work toward the best interest of the aged and provide a private place. In fact, when an elderly



person is put in an unfamiliar environment he/she may become stressed. Patients often speak faster when experiencing stress, which can cause misunderstanding. Furthermore, when patients cannot communicate with agency staff, and especially with healthcare providers or nurses, the consequences can be grave: mistrust, dissatisfaction with care, and even medical errors. Despite the health or disease information, communication with patients should be in the language with which they are most familiar.<sup>686</sup>

#### **4.3.2.3 Isolation and loneliness**

Isolation and loneliness are common difficulties that face elderly individuals in Islamic countries, and in many other western countries as well. It causes a significant adverse impact on personal well-being. Research demonstrates that social isolation and loneliness have detrimental consequences for both the mental and physical wellbeing of the aged.<sup>687</sup> The results of isolation and loneliness can prompt sudden cardiovascular problems and sudden death in some cases. In contrast, the physiological effects of social engagement and keeping social bonds can improve bodily activities and decrease illnesses related to anxiety.<sup>688</sup> The Islamic principles urge doctors and families to undertake the liability of guaranteeing that the needs of the aged are being met sufficiently. Additionally, Islamic societies believe that social connections are very imperative during old age; for instance, patients who have a blend of interpersonal relations encounter better health rather than the individuals who are socially isolated.

As a matter of fact, researchers have proposed various meanings of loneliness, as well as differences concerning loneliness and aloneness.<sup>689</sup> Loneliness is referred to as a discrete, subjective idea associated with the target social circumstance, yet not

synonymous with the actual events. Consequently, individuals can feel lonely in the company of others or be unaccompanied by anyone without feeling lonely.<sup>690</sup> It likewise has been shown that loneliness is an awful and unbearable experience. The focus on aging and loneliness has grown not long ago for two essential reasons. First, loneliness is a socially predominant experience among older individuals. For instance, in a case study of British older individuals residence, almost 40percent experienced loneliness to some level.<sup>691</sup> Comparable predominance percentages were discovered in Finland for a random example of elderly individuals age 75 and above.<sup>692</sup> Furthermore, Theeke reported that a proximately 17 percent of individuals aged 50 or more are feeling loneliness in the United States.<sup>693</sup> Second, loneliness can have harmful impacts in many areas of an elder's lives, involving both physical and psychological safety. In the Chicago Health, Aging, and Social Relations Study, loneliness was connected with hypertension, even in the wake of controlling for demographics change, health activities, and different psychological and social components.<sup>694</sup>

Also, a longitudinal study conducted on elderly individuals found that loneliness has forecasted mortality among them. Alongside consequences on physical wellbeing, loneliness is connected with low psychological well-being. In several research studies, more loneliness was linked to greater degrees of depression. Additionally, loneliness continues being a risky cause for depression after essential demographic, psychological, and social components were considered.<sup>695</sup> Loneliness has further observed to be adversely connected with emotional well-being,<sup>696</sup> and positively connected with real considerations of suicide.<sup>697,698</sup> Moreover, a study conducted for older adults in the United Arab Emirates aged 60 years and above, reported that elderly individuals who

were not fulfilled with life were diagnosed with depressive illness, fear issues, and mental disorders. There was no solely major impact on physical issues. As a matter of fact, participants who were not fulfilling of life were more prone to have a depressive issue. The substantial impact of a mental illness as opposed to physical issue proposed that an absence of significance and value were more harmful to life fulfillment than physical weaknesses. Thus, satisfaction with life is commonly examined to be an important part of individual health. Many have recognized joy with it, and some uphold that health involves mainly in having fulfilled life. Moreover, elderly people who live by themselves or just with spouses have been observed to have less life fulfillment than colleagues their age who live in a large family. The outcomes propose that giving family bolster by not permitting older individuals to live alone might be particularly useful and beneficial for elderly people.<sup>699</sup>

In fact, isolation and loneliness are not complete results of the aging process, but rather life events connected with older age, for example, retirement, health deterioration, and mourning do put individuals in more grave danger. In the meantime, components such as a great neighborhood and social environment can help protect elderly people. Acting to lessen the harms of isolation and loneliness is vital, and the consequence of not doing so can be serious. Feelings of aloneness, depression, pain and pressure frequently go concealed by people in general and, as a result, these issues have a tendency to be neglected. If moral and humanitarian reasons are insufficient, then unquestionably the expense to the wellbeing and social frameworks should doubtlessly present the defense for activity around this area. Physical health deteriorating because of isolation and loneliness likewise costs money. In general, society loses out on the contributions that

underestimated elderly individuals could be making. Therefore, lifetime homes and communities that are suited to an aging society should be planned for: For example, more public spaces convenient to elderly people; well-organized sidewalk so that older individual are less at-risk of falling or stumbling; transportation stops arranged for them that are not, for instance, at the highest points of slopes where it is hard for them to reach; different options for transportation for those who cannot utilize buses due to health reasons. Without these sorts of adjustments, elderly individuals will stay isolated in their homes.<sup>700</sup>

In general, good health is something people underestimate until it begins to vanish. In older age, pain can start to make itself known in many ways, which can keep individuals from joining in basic daily exercises. Simple things such as carrying shopping or cleaning the home can turn into challenges, not to mention keeping up more dynamic leisure activities. Having the capacity to get out and move around is critical to personal satisfaction, and losing this ability can be hard as movement comes up short or because incontinence means being stressed over the accessibility of public toilets. Sensory loss can likewise contribute to being isolated. For example, hearing loss can imply that somebody who used to talk to people at gatherings or different social events can no longer collaborate. In these instances, it becomes hard for an individual to do things that he/she used to do, and this change can affect his/her self-esteem and respect for identities. For example somebody who used to travel and visit family or friends might never again have the capacity to adapt to the usual transportation, as it could be overwhelming and harmful. Nonetheless, low-standard services to support elderly people preserve self-confidence, and interpersonal relations are also dropping. Voluntary groups that provide

low-level support through lunch clubs and assistance are now obliged by contractual agreement with the local authority to do what, which makes it harder to be flexible in the provisions they offer.<sup>701</sup> Furthermore, offering services that meet the older people's preferences in a way that maintains their dignity and respect to their autonomy involves identifying their nutritional needs, dementia and toileting, and individual needs at the end of patients' lives. Even though having already communicated their wishes, elderly people's needs are frequently overlooked when receiving care, which demonstrates an insensitive caring environment. Subsequently, care planning is an initial map to guarantee that care is focused on the person.<sup>702</sup>

Dignity, as a social fact, is the respect due to people for the autonomous direction of their activity. Respect means we assign a value to individuals' actions and allow them to exercise their powers within limits they set for themselves. Dignity, therefore, is a relation between a person, his/her purposeful action and some others who are witnesses to that action. Dignity cannot exist in isolation. Dignity for the aged requires the active response of all with whom they interact. The most important realization we can come to about dignity is that it is a social phenomenon, which is always incomplete as the isolated stand of an individual.<sup>703</sup>

#### **4.3.3. Elderly access to health care**

In Islam, access to health care is an important right of the individual. Aging is a life-long process, and society's changes across all boundaries of race, sex, and nationality will affect human life. According to the World Health Regional Office for the Eastern Mediterranean Regions, there is an increase in the number of elderly aged 60 and more.

In 2000, the percentage was around 5.8 percent (26.8 million) of the total population; in 2025, it is projected to increase to 8.7 percent, and by 2050, it will be nearly 15 percent of the population.<sup>704</sup> In addition, the rising numbers of the elderly in Islamic countries stress the need for more health care resources and accesses.

A study conducted in Saudi Arabia concerning the quality of primary health care shows that just 40-68 percent of elderly people with diabetes were referred for optical examination. The routine consultations visits were brief and, in cases of a lack of patient's compliance with clinical instructions, all were connected to low education and training level.<sup>705</sup> According to Al-Ghanim, the elderly are less likely to be fully educated, have less health access, and are less likely to know where to find access to health care. The elderly at health care facilities have chronic illness, physical weaknesses, severe disorder; most of them are in poor health and have psychological conditions, and they need assistance with personal care.<sup>706</sup> Moreover, the United Nations Economic and Social Commissions for Western Asia (UNESCWA) projects that in the period of 2010 to 2050, the elderly support ratios in the Arab world would witness a great fall. Currently, United Arab Emirates (UAE) and Bahrain have high elderly support ratios because of importing workers. However, with the increase of domestic populations and the subsequent drop in Gross Domestic Product (GDP) per capita, the expectation is that these countries will not be able to endure importing workers at the same rate as the current one and, as a result, their elderly support ratios will fall.<sup>707</sup> In line with this, Ward adds that there is no major effort happening in both countries to train health care providers in the care of the elderly.<sup>708</sup> It is important to note that long-term care is not limited to institutions, but there is an increase in home health care services, which have some advantages related to psychosocial and socioeconomic benefits for the

patient, family, and community. The biggest advantage to using home health care is that patients who can remain in their homes have more autonomy and responsibility in their health maintenance.<sup>709</sup>

In Islamic countries, everyone is given the right to have quality healthcare. Besides, the Qur'an pays enormous attention to the way the elderly are treated. However, since most of the Muslim nations are less developed than Western states, whether economically or educationally, the access to health care and supply for social demands for the elderly is problematic. Some of the health services are not provided in the public clinics in the Arab region, and some only exist in large cities. For instance, mental health services are covered to a limited extent, forcing patients to seek treatment in the private sector. Even though Islam advocates for equal rights across all ages, there is a tendency to stream resources to younger patients, while mentally incapacitated elderly people tend to be disadvantaged. Delays in getting specialist help as a result of staff shortages and the overload works also result in delays in evaluating patients' health status, which lead to an inappropriate care service. An absence of clear care plans and insufficient guidance and awareness is a problematic for health care providers when caring for patients. Moreover, the improvements in the standards of living, the reduction of illness, and the advancement in medical knowledge have all contributed to the increases of aging population. Currently, one of the pressing problems of many elderly in the Arab region is the lack of access to health services. There are few problems regarding housing, because the family still gives protection for the old. However, the urban poor often try to handle extended families together, but the living environment is undesirable, such as living in slum houses. On the other hand, individuals with higher-incomes can bear the cost of the larger

homes and household aid, which make it easier for them to host all members of the family.<sup>710</sup> It is the middle-wage family in which an older relative is sent to institutions, because the wife is working and no one is able to provide the care needed for him or her. Commonly, families are hiring a house assistance, which is in addition to the housework load; he/she is taking care of the elderly individual in the family. The duties involve basic human needs such as feeding, dressing, and cleaning. The issues associated with this type of care are that there is a great chance that the imported workers have no skills and experience of caring for elderly. Also it is common that elderly people have no options on refusing or accepting the care, and the elderly face language barriers in most events. The Islamic societies are strongly dependent on this kind of care provided by unskilled housemaids to the elderly; however, the issue with the ability to provide the same kind of care in the future and how might they be trained to do so is still in question.<sup>711</sup> Good care means keeping a balance between professional treatment and human relatedness.<sup>712</sup> Usually offering support, keeping company, mental caring, bodily caring or having a conversation is supplied by professional caregivers.

As the families in Islamic countries are more adapted than public institutions in caring for their elderly, health planning, emotional, social and economic support to family members who care for their elderly should be offered from governmental and non-governmental agencies. Another study among elderly Arabs stated that increasing urbanization and decreasing social integration of the old makes them more prone to victimization, neglect and abuse.<sup>713</sup> Also, some authorities from Islamic countries question the assumption that families can continue to maintain this cultural tradition and care for the older members.<sup>714,715,716,717,718,719,720</sup> However, a good example that aids in



supporting elderly care can be found in Kuwait. The government is in charge of delivering assistance for elderly people with illness or disabilities. They also hold legacy rights of the elderly based on the Islamic law principles. Kuwait is considered to be one of the most developed Arabs countries that have improved elderly rights. It has a wide-ranging health program for elderly people, such as free in-home health services and specialized laws concerning the social care of older citizens.<sup>721</sup>

According to Paul Farmer, a physician, and medical anthropologist who focuses on the ability to access quality healthcare even at a basic level, “lack of access to the fruits of modern medicine, and the science that informs it, is an important and neglected topic in bioethics and medical ethics.”<sup>722</sup> In the applied system of bioethics, the inquiries concerning access to health services come under the principle of justice i.e., equality, right to and fair allocation of resources. Emanuel breaks down the issues of justice in healthcare in to access and allocation, which includes rights to healthcare, the qualification of the service, and the difficulties to such facility.<sup>723</sup> According to Tadd’s study, elderly people feel that access to care is not allocated fairly, and that ageism is common among health care and social care; this perception occurs due to their feeling devalued by society. Participants in the study criticize the acute care services, as not being attentive to them compared to the other groups of the society, which again devalues their worth and damages their experience of dignity. It is additionally asserted that community physicians or specialists refuse the elderly access to advanced medical treatment, and they report that when they complain of symptoms, the answer is “What do you expect at your age?”.<sup>724</sup>

Another example for the problematic access to health care is a 91-year-old female, who fell from the stairs and had broken ribs and severe immobilizing calf harm. She was in the ER on a trolley for eight hours, then was admitted to the ward for six hours before she was moved to another hospital, with another 10 hours at that ER, without any beverage or food until the her daughter arrived, before being admitted to another ward. After 18 hours, she was transferred back to the first hospital, waiting again in the ER until a bed was finally located. As a matter of fact, the patient did not receive any considered examination or treatment during the whole process. A few staff observed what occurred with lack of concern.<sup>725</sup> According to the explanation of Lothian and Philp, this type of cases occurs due to inadequacies in training.<sup>726</sup>

Today, the world has seen numerous amplified care facilities that are dedicated to care for the old. However, in Islamic countries, vulnerable and frail elderly individuals are still receiving care by the family. Yet the region is fortunate with secure family, and often-tribal bonds, that represent a great way of support for the elderly. Also, employment of a caregiver or a private nurse is another way of help. Sending an elderly individual to a nursing home is still considered a social shame and is seen as an improper way of caring for any person. In addition, home care programs are accessible and are commonly allied with major hospitals. Yet the availability of geriatricians and other specialized health care providers in this arena is still very small. Education and training in the Geriatric field needs to give more consideration to this serious issue. There are currently no training programs in care of the elderly, and this important subject has not made it yet to the curriculum of medical schools in many Islamic countries.<sup>727</sup>

#### **4.4. Conclusion**

In Islamic countries, people are theoretically free to choose their medical treatment, but practically they rarely do it alone without the family involvement. Patients' decisions reflect, to some degree, their images of how people see them, and how their decisions can influence the course of their lives. The individual's comprehension of how others view him/her forms their inside knowledge. Furthermore, their inside knowledge, never final or complete, indeed, is constantly open to changes of self-comprehension in light of new events. Thus, an individual's personality and values are shaped through a system of human relations. Yet, in Islamic countries, an individual's autonomy to choose treatment does not imply that the choice is ethical, or that the family or surrogates should simply acknowledge his/ her decisions as fundamentally right. The individual autonomy of decision making works according to certain acknowledged limits, regardless of the fact that the law permits it.

Even though personal autonomy remains a vocal point of bioethics, in Islamic societies it is not an absolute right of the individual but rather a joint obligation between the physician, patient, and family. Accordingly, the examination in this chapter determined that sharing responsibility is not seen as undermining patient's autonomy, but rather as enhancing a patient's ability to make decisions, based on mutually- accepted goals factoring in the patient's spiritual, cultural, and health demands. This mutual understanding is attained through communications between elderly patients, family, and health care providers. Muslim approaches to moral dilemmas demonstrate that the rationality of autonomy is a resolution in medical care, and the goal is to find a settlement

between Islamic legacy, cultural knowledge, and advanced medicine, as long as basic Islamic doctrine is not violated.

The application to the ethical principle of respect for autonomy in Islamic countries fails to fully integrate Beauchamp and Childress's principle of respect for autonomy in family center societies.<sup>728,729</sup> In many circumstances, the concept of autonomy appeals to relational autonomy rather than to an atomistic concept, which recognizes the individual's relation to the family. The characteristics of Islamic countries' sociocultural framework and health care structure, which depends on the merging of individual responsibility and governmental support care, have contributed toward embracing a relational autonomy and a loss of individual autonomy.<sup>730,731,732</sup> Yet this ground of relational autonomy frameworks also appeals to families within a cultural backdrop that emphasizes the familial role in care provisions and develops the belief that maintaining hope will prolong life; thus, they need to protect their elderly from the bad news.<sup>733,734</sup> Finally, this approach causes concerns regarding the principle of respect for autonomy. In light of a lack of clear limits to the influence of the family on patient autonomy and a lack of minimum care standards that potentially compromise the best interests of the patient, education and training on the importance of respecting the individual's autonomy and its role in safeguarding human dignity are required by health care providers, institutions, and society.<sup>735</sup>

Furthermore, in spite of a lack of awareness on advance directives among many older Muslims, the discussion shows that many individuals are responsive to it, when it is carefully explained. Hence, applying the notion of an advance directive should be carried out through additional education for the population. In order to enhance knowledge and

establish an open and genuine communication between specialists and patients at all times, physicians should be obligated to have a discourse with elder individuals first, and then their family on the subject related to patient care. This conversation should be carried out without being detrimental to the outcome. Also, Living Wills can be an effort to appoint the will of the person in governing the last phases of her life. However, this concept and its importance is uncommonly recognized in Islamic cultures, and without educating health care providers on the concepts of dignity and respect for autonomy, which later will lead to public awareness of respecting elderly people wishes for wellbeing that related to their desires on earlier life, it will not be easily accepted in the Muslim world.<sup>736</sup>

Dignity in old age, and at every age, requires respect for people, compassion, and caring. An ethic for aging relies on the principle that the losses of age do not detract from a person's essential autonomy. Care should be provided without assuming that older people are different from those of other ages. Being declining and weakened individuals, whether physically or psychologically, does not make them less equal to the rest of human beings. Here and now, everyone is committed to showing each other respect and treating them well. Everyone should attempt to respect the life that incapacitated persons still have; even the most vulnerable people should be valued and cared for. The elderly person's past wishes and beliefs are not the only issues applied to what today's society owes them, but also their presented good, and value as human beings require providing the best and most ideal care for them. The change in the balance between old and young generations highlights issues of human values and respect, and whether this condition is related to age. Ethically, it is argued that older people should be treated the same as any

age group; for example, they should not be discriminated against, and they should have the same rights and responsibilities as anyone else.<sup>737</sup> Moreover, elderly persons should have the personal liberty to choose and decide on their actions from plans or alternatives that are available. For example, the right to remain in one's home reflects a respect for personal autonomy.

In Islamic countries, a considerable measure of thought, research, education, and preparation are all needed to meet today's challenges of the increasing number of elderly people. Despite the fact that the region is still fortunate with solid family bonds and good individual resources, the load of caring for the old can no longer be neglected and left totally to the family. Recently, numerous institutions have appeared to deliver care for elderly people. But arrangements for services that supplement ethical care are needed. Also, caution should be considered to avoid the thinking that such an approach toward care is a duplication of the Western framework; thus, customizing it to the local culture and standards would be supportable. In this regard, the World Health Organization recommends that addressing the requirements of elderly individuals in the developing countries, including Islamic countries, should be developed according to the care system of that typical population. There is a need for geriatrics care; educational institutions should begin setting the foundation that can deliver satisfactory routes for health care providers who are responsible for achieving the best health for their patients.

Care is in the first place a relationship between individuals. On one side there is an individual who, because of illness or physical difficulties, cannot take care of him/herself and is in need of support by another person. On the other side of this relationship is somebody who can supply this support: family member, friend, and

voluntary or professional caregiver. The reason these other individuals offer help and support is because they are concerned about the needs of the ill or vulnerable person; they identify their needs and want to help.

Finally, health care institutions and providers are still viewing elderly individuals as a burden. Furthermore, elderly people still feel excluded from receiving better health and life-saving treatment. So far, the world developments have seen much greatness, and improving longevity should be something to admire, not to regret, while certainly elderly people should not be viewed as problems at all. The negative picture of the elderly as a group has massive ramifications that negatively affect the delivery of such treatment or services. This attitude has been challenged and has been successfully countered in many Western countries. Older individuals can contribute to the health care providers in delivering such changes in the future of health care delivery.

In later life, illnesses and chronic diseases tend to be frightening for many elderly individuals, so health experts will be involved in the elderly caring for much of their professional life. The challenge is to make sure that all health care workers have the capabilities to convey appropriate care and treatment with respect and appreciation to the elderly individuals' dignity. Many voluntary local gatherings in Islamic countries have drawn in with local health care organizations and have plans of arrangements that have included older individuals in the improvement of their health.

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## **Chapter 5: The justification of how respecting human dignity and personal autonomy can help to improve elderly health care in Islamic countries**

### **5.1. Introduction**

The Quran states that the elderly should be respected and valued by their relatives.<sup>738</sup> This statement is true to life not only in the framework of family relations but also when speaking about health care delivery. Beside the longevity risk (facing death), elderly also face a declining health status commonly associated with aging. The Quran also says that aging presents challenges to elderly individuals. This is because aging is a multifaceted course of physical, mental, and societal modification. The effect of aging is illustrated in the declaration, “If We grant long life to any, We cause him to be reversed in nature, Will they not then understand?.”<sup>739</sup> Thus, elderly people are more likely to experience injuries, in addition to health concerns such as Alzheimer’s, depression, arthritis, heart disease, etc.

Certainly, there is a need for physical, mental, social, and financial preparation to alleviate the negative effect of aging on an individual’s wellbeing. Many older persons are not able to manage everyday activities without support. Commonly, they receive assistance from their relatives, but when the issue turns out to be more critical, they approach outside caregivers. The way health care providers, patients, and the family interact with each other tends to affect the condition of the patient and his/her health outcomes. However, the provision of daily care alongside the necessary clinical procedures is not enough for the wellbeing of the elderly. Nursing home residents, for instance, stress that the sense of autonomy and dignity are crucial for an individual’s

emotional as well as physical state.<sup>740</sup> Consequently, many residents of nursing homes have to fight for their right to make decisions and remain autonomous.<sup>741</sup> It is necessary to add, that elderly people face similar challenges even if they are at home with their family, as younger generations tend to make decisions for them thinking that the older adults are unable to do so.

Several research studies have shown that many elderly individuals no longer want to be dependent on their children, especially with a long-term obligation, e.g. personal care resulting from a chronic disease.<sup>742</sup> Such changes in preferences for care are emphasized by research on changing forms of family commitments. Finch has underlined the various rules defining the anticipation of family care. She reports that kinships do not work according to a standard set of moral guidelines for elderly people and their caregivers to follow.<sup>743</sup> Usually, the obligation that symbolizes the distinctive character of kin relationships do not follow a consistent way of social practice. In the same vein, Decalmer and Glendenning declare that caring for an older person is not defined by any clear social norms (in contrast to care for children). The reasons are not just that older people are adults and hence supposedly in control of their lives, but also that issues of who should provide care and on what terms are in a state of constant change.<sup>744</sup>

The health care environment is shifting in significant ways; the public is becoming increasingly educated, the numbers of facilities are increasing, and blind trust in medical professionals is gradually vanishing. Consumers and caregivers are vigorously requesting a more equal status.<sup>745</sup> Although technology developments potentially expand healing, at the same time they are increasing financial and ethical pressures regarding access to health care and the virtual balance concerning care and cure.<sup>746</sup> Undoubtedly,

current media is spreading information about this subject and the public is worried about low standards of care for the elderly. Therefore, there has been an important readjustment of policy, with the new standard of quality in the National Health Service (NHS).<sup>747</sup> The National Service Frameworks (NSF) changed their attention from patients with particular conditions towards more heterogeneous groups such as older people.<sup>748</sup> Thus, geriatrics is a distinct field of knowledge that helps to provide the necessary quality care with efficient outcomes that elderly need.

In Saudi Arabia, elderly home health care has become an essential service of health care delivery. In Islamic countries, specifically in the Gulf States, there have been a few reports on the health profile of the elderly. In 2011, a study administered in Saudi Arabia showed that 50.4 percent of elderly had more than four chronic health illnesses.<sup>749</sup> According to their data, the elderly account for 5 percent of the total population,<sup>750</sup> that is 16.9 million. A study in the southern region of the country revealed that the elderly attending home care facilities were suffering from many chronic disorders. Subsequently, common co-morbidities need a preventive, curative, and rehabilitative program in improving the quality of health among elderly patients in home care settings.<sup>751</sup> In regards to compassionate care and the behavior of some primary health care workers, participants experienced a lack of sympathy in care. The southern region study declares that primary health care (PHC) providers are possibly frustrated by workload and overloaded agendas. Concerning the ‘informativeness’ of care, some elderly people were displeased with the health education offered by the PHC providers. Thus, the whole health group needs continuing medical education programs to be prepared to handle their duties in health care. Also, elderly health care services may benefit from an outreach



approach that makes both clients and providers aware of the availability and usefulness of a range of programs to report several problems.<sup>752</sup>

The same trend is spotted in the United Arab Emirates (UAE); the ratio of the older population is growing. The ratio of the older population in the UAE was 5.1 percent in 2000 for ages 60 years and above and is estimated to increase by more than four-fold in 2025 (23.6 percent). In addition, in 2000 to 2013 life expectancy had increased from 74 years to 78 years. This could be credited to the developments in the standard of living, health care services, and prevention of many communicable diseases.<sup>753</sup> The quick development and social transformation in the United Arab Emirates have brought change in the family structure from the extended household towards the nuclear family. This transformation has interrupted the family support framework, resulting in social isolation that has led to many psychological disorders among the elderly. Furthermore, these losses and frailties among the elderly increase the possibility of physiological disorders. It has been recognized that the elderly are more vulnerable to psychological problems and depression.<sup>754,755</sup> It is estimated that 38.3 percent of the elderly patients have depression. Such mental disorders should be identified and treated during an early stage to inhibit deterioration and improve the quality of an elderly person's life.<sup>756</sup>

In addition, services for the elderly and chronically ill in Saudi Arabia are very limited. No specialized geriatric services are provided in the main hospitals; the elderly are cared for in general hospital wards and are treated by general internists. In some regions, a minimal number of beds are provided in primary care hospitals that serve older persons in addition to caring for others with chronic disabilities. New charitable geriatric and rehabilitation centers will shortly be open in Saudi Arabia. Other health services have

been initiated but on a limited scale in some regions, and these include home care services and special minimum care hospital projects. The decline in extended family structures may also result in increasing pressures for older people to become institutionalized more often than in the past.<sup>757,758</sup>

There is almost no health or social support for the majority of elderly people outside the family. The focus for most Islamic countries is on child and maternal health, while health care for elderly people is neglected. Both health care facilities and skilled staffs are absent. In addition, health workers who are the first to interact with the elderly are inadequately trained or equipped to care for them. General outpatient departments provide care, but there are long waiting times, the care is often inadequate, and minimal attention is paid to personal care and counseling. Separate inpatient facilities are rarely designated for elderly patients. As a matter of fact, gerontology is not a popular specialty.<sup>759</sup>

In this chapter, the focus is on the positive influence of the moral principles of dignity and respect for autonomy on elderly people's health. The discussion offers a lesson from the West, which involves the ethics of caring for the elderly and human responsibilities, an elderly care focused approach in maintaining the dignity and autonomy of older people, and the home site of care. The chapter emphasizes that the Western health care structures devoted to the principle of respect for autonomy cannot be simply implemented in the health care in Islamic culture. However, the discussion demonstrates what works and what doesn't in health care practice in Islamic countries, which aids in structuring a better understanding of how the ethics of dignity and respect for autonomy can be tailored according to Islamic culture. Only if they are considered in

the framework of the health care system, the ethics of caring can be managed decently. The discussion will consider the ethics of caregiving, as it is actually applied among family members and an array of medical professionals intimately involved in providing care. The goal of the analysis is to explore how devoted caregivers should approach treatment decisions in a range of complex clinical situations, always aiming at the best care for the person and always working within the ethical boundaries articulated in the previous chapters. This ultimately fosters both notions of the concepts and improves an elderly person's well-being. The aging of the entire population, and the growth of the very oldest segments within it, are associated with the transition from informal to formal home health care delivery. Thus, a need for a fresh look at ethics in the home, institutions, and community will be elaborated. There is a need for raising the standards of educations and attitudes through training, which will be the key targets to providing a dignified and respected health care to the older population in Islamic countries.

## **5.2. Lessons from the West**

Freedom and autonomy are critical when speaking about caring for the older population. Even if the patient's condition requires constant interventions, it does not mean that he/she is becoming totally dependent.<sup>760</sup> An elderly-focused approach has become the most widespread paradigm in Western countries. Western healthcare professionals have adopted a holistic view concerning health, which is also shared in Islamic countries.<sup>761</sup> Caring for patients, especially when it involves the elderly, requires health care providers to focus on the physical, mental, and emotional wellbeing.<sup>762</sup> The needs, interests, values, and expectations are all considered when treating the elderly.

Clearly, autonomy and dignity are of paramount importance when caring for the elderly. These two concepts are ensured by health care professionals through their use of the holistic approach when caring for the elderly. This approach involves addressing all aspects of elderly people's needs. These aspects include provision of all the necessary clinical procedures (tests, injections, message, etc.), care procedures (bathing, changing clothes and so on), wellness procedures (physical exercise, art, etc.) as well as emotional support (little discussions, group discussions, activities, etc., that promote their emotional health). This comprehensive care ensures the patients' wellbeing in health, emotional, and psychological conditions. It is necessary to add that the majority of Western nursing homes are very successful in the implementation of this paradigm. The elderly and their caregivers are much more satisfied with this holistic approach.<sup>763</sup>

Across the world, older adults generally prefer staying in their homes rather than moving to a nursing home. Health care personnel shortages are one of the main reasons that have led to the deteriorating quality of services elderly patients receive.<sup>764</sup> The turnover rate of health workers in the geriatrics field is between 50 percent and 100 percent per year,<sup>765</sup> which has adverse effects on the quality of services provided. This is also linked to the diminishing quality in screenings and physical examinations, which pose certain threats to the quality of services and the wellbeing of patients.<sup>766</sup> Another reason older people are reluctant to go to nursing homes is the fact that they feel more empowered in their own homes. Their family's care makes them feel more autonomous and dignified than they would otherwise feel in a nursing home. Though it should be noted that people do not have an entirely negative view concerning these facilities.<sup>767</sup> Many people understand that these are proper solutions for those who have significant health problems. It is a prevailing view

that a nursing home is a place where the elderly can receive high-quality care. Western nursing homes are improving as the government attention to this sector increases.<sup>768</sup> Various programs and the wise allocation of funds are leading to the development of high-quality nursing homes in this region of the world. These Western countries have made continuous efforts to improving elderly health care service options and to reducing the ethical dilemmas that are associated with elderly care.

In the Eastern Mediterranean region, health care organizations are tasked with providing quality health care to their people. But, caring for the elderly has not been given adequate consideration in most countries in that area. In fact, geriatricians are rarely found in the area. Most health care professionals do not possess the basic education required to attend to the elderly.<sup>769</sup> The representatives of the health care systems in Islamic countries should consider the way their Western colleagues have accepted geriatrics and the way that they care for their elderly.<sup>770</sup> Of course, it will not be easy to reform the health care system and force medical professionals share new views. But the first steps taken in the Western region of the world should make it easier for health care professionals in Islamic countries to acquire this knowledge and tailor it to their culture's needs. It is also important to change the public perception of health care and the elderly. People must understand that specialized healthcare facilities, like nursing homes, are not there to get rid of the problems associated with caring for the elderly. They must see this specialized form of health care as an opportunity rather than a hazardous scenario. It is simply another level of care when home care is unavailable. A British study has shown that professionals in the West have already started to educate families in regards to the many options elderly care has to offer; whether in an institution or at home. This

approach is valuable when the services are provided with respect for people's autonomy and their desire to feel dignified and independent as long as possible.<sup>771</sup>

The importance of dignity for the elderly has been given a lot of attention in Western countries. As a matter of fact, public education, social policies, and the media have all helped in shaping a more positive image for the elderly. In the United States, this has already been happening, thanks to the rising number of baby boomers, who have the decisive influence and resources to change the common stereotypes of aging. Culturally older individuals have been increasingly represented as vital, active, involved, and admirable.<sup>772</sup> The experience of Western countries shows that extensive media coverage can lead to a shift in policy-making and healthcare provision.<sup>773</sup> In Europe, the debate brings policy-makers, practitioners, the elderly, families, and the community together, which has resulted in the development of a positive view of nursing homes.<sup>774</sup> The focus should be on the concept of dignity and respect for autonomy, and the Arab people should understand that caring for the elderly can be delivered through nursing homes and other caring facilities. Children do not hand over the responsibility of care for their parents but instead bring another level of care, which involves professional assistance. The elderly can still feel that they are the core of the family even while living in a nursing home. These messages should be delivered through the media, which has the power to shape public opinion.

While the need and usefulness of geriatrics as a medical specialty is just now being discussed in the Middle East, scientists from the UK underlined its value many years ago. Geriatrics has received much attention over the years in the UK leading to an increased awareness and knowledge of this specialty throughout the region. Remedial therapists and

social workers are cooperating with nurses to make professional contributions to geriatrics. In fact, the Hippocratic Oath, which is a model code of professional ethics, describes what physicians *ought* to do, and *ought not* to do. The Oath sets up medical knowledge that “generates obligations in those who possess it.”<sup>775</sup> Therefore, improving the quality of care and patient well-being, and decreasing health care inequalities are special obligations for physicians, health care organizations, and medical educators; and it requires an increase in collective and collaborative works. Hence, the Hippocratic Oath will be worthy of community support only when the medical profession demonstrates in a meaningful and clear way that it is meeting its social and public obligations to make not just health care, but the entire world a better place.<sup>776</sup> The modern version of the Hippocratic Oath states that physicians, “will remember that there is an art to medicine as well as a science, and that warmth, sympathy, and understanding may outweigh the surgeon’s knife or the chemist’s drug.”<sup>777</sup> Physicians also “will remember that they do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person’s family and economic stability. Their responsibility includes these related problems, if they are to care adequately for the sick.” These statements prove that warmth and compassion can at times be more important than the actual medical care one offers. In addition, it shows that considering a patient’s physical, psychological and social conditions are all an important part of health care. The concept of care refers to a set of activities that include maintaining and restoring the body, mind, environment and everything that affects a person in any way.<sup>778</sup> Physicians and healthcare leaders are obligated to create systems that best honor these aspects of patient care. Geriatric specialists allow their patients, who were previously thought to be almost

untreatable and assigned for long-term care, to restore their independence and live an ordinary life.

Until the second half of the 20<sup>th</sup> century, geriatrics did not attract a lot of attention, and practitioners, as well as theorists, tended to focus on treating particular diseases rather than diseases within particular age groups.<sup>779</sup> One of the reasons for the increase in geriatric care concerns was the rising number of elderly. The issues became prevailing at the end of the 20<sup>th</sup> century and have continued into the 21<sup>st</sup> century as the number of people over 60 has continued to rapidly grow. It has been estimated that individuals over 60 will constitute around 20 percent of the population of the world by 2050.<sup>780</sup> In 1996, the social work administrators and philosophers decided to cooperate and create a new program that would enhance the care for elderly people. Researchers note that there is a need to establish a program for those providing home care to elderly patients.<sup>781</sup> One of these programs was created in the USA by professionals from different spheres related to caring for the elderly, including ethics, community services, and health. Primarily, the program was designed to help the staff cope with arising issues. The major change that later influenced the whole vision of ethics was implemented due to the practitioners' goal in assisting clients enter the last stages of their lives with a sense of dignity and self-identity.<sup>782</sup> Of course, it does not mean that practitioners should be totally responsible for such things; still, they are expected to do their best. Several years' later, ethics and aging started to be considered and designed as practical concepts, and models for care.

Another interesting lesson concerns elderly people with dementia. At the end of the 20<sup>th</sup> century, dementia had become one of the major community care problems, because many elderly populations suffered from it. British practitioners have used a



broad range of facilities when caring for patients with dementia. First, they divide all elderly patients into two main categories: those who have relatives that care for and look after them, and those who have no support or whose relatives will soon not be able to manage such activities due to personal disabilities.<sup>783</sup> Care for these two groups cannot be offered in the same way, and it requires adaptation. If the patient has a family, the specialists are focused on making the lives of relatives less overloaded. Thus, it is vital to cope with patient's insomnia, aggression, restlessness, etc. In this way, professionals prevent a crisis and allow the family to keep a positive approach. They can remove the older family member for some time when one is an added burden. The symptoms should be alleviated and regular provisions of assistance maintained. Such things can be done in various forms. One being a day care with a flexible schedule so that a professional will take care of an older individual when the rest of the family is at work.<sup>784</sup>

Intermittent relief admission looks after the person in different ways, including support on holidays and on a regular basis.<sup>785</sup> Such practices are beneficial during the advanced stages of symptoms. The patient receives high-quality professional treatment and the relations with family members do not spoil. Moreover, it is a great way to reduce the overloading of long-stay residential and hospital services. This approach is likely to be advantageous for the Islamic countries, as it allows the families to take care of their relatives as long as possible, which is critical for them. For this approach to be successfully implemented, the primary care workers should take the cases as early as possible.<sup>786</sup> If the patient has no family, the priority changes to the needs of the elderly. The professionals can provide services at home and come to the client. It can be managed if one is not in critical condition, as people with dementia require constant assistance. The elderly

are mainly encouraged to enter residential facilities where various professionals look after them day and night. They try to make patients feel as if they are at home.<sup>787</sup> However, for clients of nursing homes, the staff and surrounding patients become their adopted family as they share their concerns, fears, hopes, and happy moments. In this way, British scientists underline that the emotional aspect should be considered even more valuable than the medical one.<sup>788</sup> Of course, it is vital to control all symptoms, but it cannot be managed if the patient feels nervous or frustrated, which proves that one should be treated ethically.

According to the Peach and Pathy study in the attitude of caring for the aged among students involved in geriatric ward versus general ward, students trained in the geriatric ward have more favorable attitudes than those attached to a general one.<sup>789</sup> The study also reveals that training in geriatrics has a positive result in the student's attitudes. In addition, the evidence indicates that enhancing education and training to focus on elderly care will lead to a positive future experience when dealing with older individuals. Many scholars have written about the importance of healthcare providers dealing with elderly people who are healthy, as well as those who are patients.<sup>790</sup> Improving and increasing training and experience will promote the geriatrics status, yield a positive impression on attitudes and inspire more people into the field, that in turn will benefit elderly patients.<sup>791</sup>

The necessity to improve geriatrics, which was emphasized by the British scientists and practitioners,<sup>792</sup> was also supported by the US specialists, who made a significant contribution to the ethics of caring for the elderly. The project "Home-and Community-Based Services for Elders: An Ethics Resource for Providers," attempted to assess the opinions of the stakeholders with the focus on care providers rather than patients and their

families.<sup>793</sup> The findings yielded by the program also emphasized that dignity and autonomy of the elderly are affected if the caregivers fail to consider them, which leads to more critical problems. As a result, a training program for workers to improve their performance was designed. It was mainly based on the everyday life ethics. The scientists pointed out that care should be managed according to the consumer-centered approach so that the patients feel they are valued. They emphasized that the professionals that closely interact with the elderly should take into consideration how they greet them, do they have a trusting relationship and how to build it, and how to care for a particular patient, etc.<sup>794</sup>

Unfortunately, many people think that simple things are part of a simple routine that does not require any special approach. Based on that, they treat the patients in a way that does not appeal to them and fail to realize what spoils their attitudes. Based on this information, Holstein states that healthcare professionals, practitioners at nursing homes, as well as relatives should be aware of the elderly's needs. This can be achieved through extensive training and discussions that can result in the significant improvement of the elderly's wellbeing.<sup>795</sup> In other words, there is a close connection between the promotion and application of people's dignity and autonomy, and the patients' health.

Furthermore, several scholars have advocated the wider application and fuller development of concepts such as the 'lifetime home' or the 'smart home' in providing more efficient, and less dependency creating environments.<sup>796,797</sup> Recent studies have taken a novel approach to the application of technology, by harnessing the power of personal computers, compact disc, read-only-memory (CD-ROM), and integrated services for digital network (ISDN). These advanced technology procedures provide older people and their caregivers with direct, live, visual contact with a health center and

collaborating information on a range of topics, such as coping in emergency situations, financial advice, social security benefit availability, and choosing temporary institutional care or care at home.<sup>798,799</sup> Technological involvements could help elderly people live independently, and support their health care through monitoring and examination services.

### **5.2.1. The ethics of caring for elderly and human responsibilities**

An important difference between acute care and care for people with a chronic illness is the type of relationship between the caregiver and the patient. Relationships in curative medicine are generally brief and superficial, usually consisting of short-term contact with various professional practitioners. Care is different from cure, yet, both models aim to support people and alleviate their pain and symptoms. Care refers to a positive attitude that involves compassion, kindness, attentiveness, tolerance and participation. Although, such an attitude is also important in curative medicine where its main focus is on fighting to heal the patient, not to give up quickly, and to abstain from further extra-ordinary treatment. In curative medicine, activism is central; trying the best that one can to improve the condition of the patient. Care does not entail a heroic attempt to conquer disease, but it means support and solidarity. Caring is much more fundamental than curing. This is not only because caring tries to respect the uniqueness and value of a fellow human being; but with the increase of longevity, there will be an increase of the need for physical, emotional, and social support for individuals with long-term diseases. This growth has important effects for the allocation of services in health care organizations. Even though there has recently been more attention for an increase in long-

term care services, curative medicine is still dominant in health care. Saving lives by means of impressive medical technology is still seen as the most important task in health care.<sup>800</sup>

The chronic conditions that elderly people suffer from make them search for external help, which can be provided by family, and professionals in different locations. They suffer from changes in their bodies that are often followed by pain, losing identity and feeling lonely and powerless. Such emotional conditions can have adverse affects on the physical ones and worsens those symptoms. Care and the relationship between the professional and the patient are the main things that can improve this situation.<sup>801</sup> That is why it is critical to stick to the ethics of daily care. While the family has a moral responsibility to take care of the older relatives, specialists who work in the home or help the family manage care at home, have a professional responsibility that is vital for the professional code. This deals with ethics, guidelines, and responsibility. One of the main points is that specialists should not do any harm to the patient.<sup>802</sup> This harm may not only be physical. When a care provider limits one's autonomy and neglects dignity just to simplify the working process or because of some other reasons, it cannot be said that he/she does one's best to help the elderly.<sup>803</sup> Such limitations are also harmful to the patient, and their existence presupposes that the professional responsibilities are not maintained. Today, this mainly happens due to a lack of knowledge and particular prejudices.

People tend to believe that the elderly are not able to manage the things that younger people can. As a result, their will to provide more help turns into the creation of boundaries that prevent the elderly people from living their own lives. Elderly people who receive care from their relatives and from health care professionals reported their inability to do some

things they were capable of doing, just because others wanted to help them,<sup>804</sup> which further limits their ability to live on their own. Therefore, to be sure how to act, specialists should refer to the ethics of caring and use it as a guideline when looking after the patients. The ethical principle of justice focuses on such aspects as equality and fairness, as well as their consistent application. An ethic of care concentrates on attentiveness, trust, sensitivity to need, and fostering caring relations.<sup>805</sup> Whereas an ethic of justice pursues a balanced result between individual rights and interests; an ethic of care perceives the interest of carers and cared for as highly intertwined rather than as simply competing.

Unfortunately, the ethics of care do not presuppose autonomy, as the older population requires it. Only the combination of various concepts provides an opportunity to create a decent guideline that the professionals can follow when managing their duties and interacting with patients. In this way, it is extremely important to ensure that health care providers emphasize all mentioned aspects of ethics; otherwise, the elderly are likely to feel neglected and frustrated, which may cause serious complications in their mental state and worsen their conditions.<sup>806</sup> People who cannot manage their everyday activities by themselves and require constant help realize that they are dependent. They need to be engaged in the interaction that allows them to feel their autonomy and identity even though they are limited.

A person who has some illness requires support. But, it is vital to limit the interference for one not to become totally dependent and lose oneself. A professional should consider both ethics of justice (public sphere) and of good (private sphere). All in all, ter Meulen emphasizes that it is vital to make sure that “public life, and particularly care, is served well with an ethics that is purely based on justice.”<sup>807</sup> In this way, human rights

should be considered. Such a view is also supported by Andorno who states, “all human beings are born free and equal in dignity and rights.”<sup>808</sup> The authors of both works claim that the elderly like all other people should have the right to equal access and safeguarding of privacy. They should be able to receive, use and provide information, which is an important part of today’s world. Only if they are considered in the framework of the health care system, the ethics of caring can be managed decently. Such concepts presuppose interaction between care providers and patients. Still, it is vital to refer to the most appropriate ethics of care that puts emphasis on responsibility, engagement, empathy and similar values as they are not a part of “the contract perspective,” but are central to the provision of high-quality care to those who need it.<sup>809</sup> In this way, the ethics of caring is a complex concept that can be observed when all its components are considered.

Wilmoth and Ferraro stress that diversity is the most important characteristic of the elderly.<sup>810</sup> They have different incomes and health statuses; they are used to living in various environments and conduct distinct activities.<sup>811</sup> Of course, being at the home, a majority of older people live, work and sleep at the same times, and their everyday activities are managed in groups where everyone is equal, which seems to make them alike. Some may think that all patients have equal needs, which are completely satisfied in nursing homes. However, the staff of the nursing home would not be able to focus on all patients at the same time if they were occupied in various activities all day long.<sup>812</sup> The existence of a schedule tends to simplify their tasks and ensure safety for the elderly. The personnel understand that it is critical to help people feel better. Thus, they manage their duties including but not confined to delivering medication, bathing, changing clothes, implementing various clinical procedures, and so on, so that the patients feel independent and dignified.<sup>813</sup>

It is critical to remember that the family and professionals are responsible for providing decent care to the elderly. They should consider the situation in different perspectives and do their best to make the older people feel valued and powerful. It is not enough to consider just one aspect of ethics in this perspective. It is important to remember that elderly people share equal rights with the younger generations and should receive both standard treatment and help on an everyday basis. Sadly, many people today tend to believe that the elderly need more care and support than other individuals, because they are vulnerable and weak. These views deteriorate elderly people's autonomy and dignity, and lead to their feeling of being a burden. Consequently, it will impair their emotional balance and may lead to the development of various psychological conditions such as depression, anxiety and so on. Family members' preparation to care is affected by the elderly's attitude about the care. The care depends on how the elderly see their own dependency and whether they can accept to learn and adjust to dependent responsibility. In severe situations, older people do not acknowledge the need to be cared for, and prefer their autonomy and privacy, and thus reject care even if the decision is unsafe for their health. These instances are commonly linked to depression. Others state that they would prefer living in an institution, or even dying than to become dependent on their children or on the mercy of others. However when they become dependent they do not only prefer care by their family but also expect it. This ambivalence and uncertainty often prevents them from playing the new role successfully, and it becomes a source of stress for both the elderly and their caregivers.<sup>814</sup>

Family obligation is an ancient one, and every society and even generation creates its own ideal. Care for older members of the family was always a moral norm in European



culture. It came out of the Judeo-Christian moral premise that it is human and moral to care for the old and vulnerable in the family, and in the whole society, and that the young and able have a responsibility for those who cannot care for themselves. Relationships in the family based on intimacy and mutuality should be fulfilled with mutual honor, love, and affection. Despite expressed worries that family care is declining and the willingness of family members to give care is decreasing; studies from the United States, the United Kingdom, Canada, and Sweden have documented that there is a persistent willingness to give care, and that family caregiving is accepted as a natural human experience. The majority of care is provided in the informal sector, mostly by families, with the rest coming from formal paid services provided by professionals. A willingness to give care represents only the first, though very important, step when family caregivers face the need to provide help. The next two steps are the ability to do so and the knowledge and skills necessary for care. The familiarity with home care is also very important.

Virtually all-family caregivers are without any special knowledge of nursing; yet many of the disabled elderly people need skilled nursing care. Thus, the character of the disease and impairment, the level and duration of disability, and the prognosis of the disease are of extreme importance. The level of dependency is an important objectively measurable factor and, it is inversely related to the amount and extent of care. When an elderly individual needs only emotional support, visits and monitoring, and some home help, then most families accept and manage care for many years. With further deterioration, when more help and personal assistance are necessary in daily activities such as eating, grooming, toileting, and walking, the caregiver and his family have to consider full-time caring, a

permanent co-residence situation, giving up a job, and many other things in their personal life. In this situation families seek either paid formal help or permanent placement.

### **5.2.2. An elderly focused approach: maintaining the dignity and autonomy of older people**

Aging is associated with the fear of losing autonomy, power over an individual's own living status and the activities of life due to frailty and illness. The elderly and their advocates generally favor home health care over institutionalization in a nursing home, because home health care purports to provide greater opportunity to maintain the autonomy of the elderly care recipients. In the USA, increased autonomy is one of the reasons that federal and state programs provide substantial resources to finance home health care services. Yet, many elderly persons, advocates, and analysts, note a troubling lack of autonomy in home health care programs.<sup>815</sup> As it was mentioned earlier, the elderly who require long-term care may receive it at home as well as in a care home or nursing home. British professionals state that elderly people who have serious health problems, such as dementia, need a more sophisticated level of care, but their family members are rarely able to provide it.<sup>816</sup> However, researchers also underline that a nursing home is a place where people become extremely dependent and may lose their autonomy.<sup>817</sup> The oppressive environment may lead to physical and mental issues, as well as worsen chronic conditions.<sup>818</sup>

In order for the older people to avoid mental deprivation and suffering, the health care professionals in the facility need to pay close attention to a patients' autonomy and preserve their dignity.<sup>819</sup> Several scientists concluded that dignity is the key instrument that

contributes to a person's physical, mental and emotional wellbeing.<sup>820</sup> Also, researchers claim that the maintenance of older people's autonomy is one of the priorities in elderly care.<sup>821</sup> Today, mainly the law and religion make people treat each other with respect, as they both state that people have inherited dignity, which means that others are obliged to recognize it.<sup>822,823</sup> Issues related to the contemporary culture of care mirror the need of dignity of identity. Modern care reflects people's need to remain dignified and respected.<sup>824</sup> It has been acknowledged that the loss of autonomy leads to the loss of dignity, as individuals who are not able to cope with the easiest tasks and are in need of continuous assistance tend to believe that they do not deserve the things others can easily gain.<sup>825</sup> Still, the Quran encourages always valuing and respecting the elderly.<sup>826</sup>

Islamic law holds a clear position on this matter. According to Islamic law, an individual who provides care to or supports an elderly relative in any way whether financially, psychologically, or emotionally, does not do it for this person. This is done to discharge every individual's sacred obligation.<sup>827</sup> The law also involves clear guidance to children who care for their parents. It stresses that children should respect and reveal their love to their parents. They should talk with their close ones and make sure their needs are met. According to the Sharia theory, care rights are equal for children and parents. In other words, parents have certain responsibilities to their children. At the same time, children also have particular responsibilities to their parents when they become old or disabled.<sup>828</sup> This ruling is seen as a divine command of God. Therefore, it is deeply rooted in the Islamic culture. At the same time, to apply this pattern to healthcare, it is necessary to use the approach implemented in the Western countries. In the West, ethical concerns and values

were translated into particular care procedures and codes, which can also be utilized in the Islamic world.

The law is an illustration as well as a result of the Islamic culture concerning the relationships between the elderly and younger generations. Thus, children understand that they are responsible for the well-being of their elderly relatives. The elderly also expect care, respect and support. These beliefs create strong ties within families, which makes the society stronger. Nonetheless, these perspectives also create obstacles to the provision of the high-quality services to the elderly. Older adults in the Islamic world are still reluctant to leave their houses, as they believe they will not get the care they would have received at home. People also believe it is their children's responsibility to care for them as it is written in the Quran. However, it is possible to use similar strategies that have proved to be effective in the Western world. For example, governments of Western countries allocate significant funds to improve elderly care. The issue also receives considerable media coverage, and stakeholders such as officials, elderly people, younger generations, healthcare professionals, etc., are encouraged to participate in the debate. People should understand that they would be unable to receive and provide the services that are commonly given in nursing homes if they choose to stay at home. Children do not have the necessary skills to react in cases of emergency, but the elderly can receive the necessary clinical treatment in nursing homes.<sup>829</sup> When such facilities start operating in all the Arab countries, the public opinion will change.

Despite the fact that intrinsic value appears to depend on the holding of autonomy; dignity is a personal experience rather than a moral quality assigned to others' decisions.<sup>830</sup> It gives attention to whether an individual feels dignified or undignified, rather than on

whether others see them as having dignity. Pullamn stresses that it is the respect for dignity of people that stimulates our care and concern for the vulnerable elderly individual. At the same time, acknowledging elderly dignity will too enhance the ability of health care providers to express and improve their dignity.<sup>831</sup> Beyleveld and Brownsword examine dignity and the situations in which individual rights can boom. They argue that autonomy can either support and endorse dignity or restrain it; considering it as a ‘two-edged sword.’<sup>832</sup> Furthermore, the Aristotle virtue theory emphasizes the importance of dignity as a moral virtue to achieve excellent activities.<sup>833</sup> By this account, health care professionals and nurses would not only be expected to respect the dignity of patients, but also to show dignity in their own attitudes. In fact, in Western countries, the nursing codes of ethics concur that respect for dignity is an essential value and that nurses have obligations to respect the patients’ dignity.

According to the Mann argument, the significance or themes of dignity in the Universal Declaration of Human Rights (UDHR) is muted.<sup>834</sup> Likewise, Schulman indicates that the UDHR offers an uncertain and ambiguous instruction on bioethical debates.<sup>835</sup> But, with all the government pomposity about the importance of dignity, the Department of Health points out that, their goal is to create a nil acceptance of lack of dignity in the elderly care.<sup>836</sup> However, in 2012, a call for dignity code was launched in the UK, to protect elderly and ensure that health care providers are delivering a care and treatment that respects the elderly.<sup>837</sup> Indeed, dignity is an important subject with entitlements of value and respect, and it serves a significant role in health care ethics and health provider’s value.<sup>838</sup>

Moreover, appreciating the custom of interchange for all people can alleviate or avoid the loss of dignity and autonomy of elderly people who are dependent on care due

to their weaknesses. The ability to give back is frequently overlooked as a basic social need. The aspect of interchange delivers a new approach to more efficient care, especially when psychosocial implications are involved. Undoubtedly, the status of disparity in interchange may vary by personality and may be affected by the contingency to compensate for care. Roy implies that health care providers' attitudes can significantly influence the quality of treatment and the respect given to maintaining elderly dignity and autonomy.<sup>839</sup> After all, the importance found in dignity means that it can not be neglected as a concern for health care professionals. Dignity in care is also described as one of the themes in the "A New Ambition for Old Age" reports.<sup>840</sup>

Another area which would benefit from further conceptual and empirical development is a fuller understanding of the nature and quality of interdependent relationships between older people and those providing support, whether family or formal carers. Some new insights have emerged with potential implications for the design and delivery of support. Seale, for instance, suggests that the central dilemma for carers is how to give support in a sustaining way, rather than undermining the self-identity and capacity of the care receiver. According to Seale, the elderly attempt to uphold the feeling of living a momentous life and preserve their status secure.<sup>841</sup> Holding their status safe mainly refers to being seen as independent in three important areas: self-care, maintaining a thorough physical environment, and continuing social relationships.<sup>842</sup>

### **5.2.3. The home as a site of care**

Home health care is defined by the National Clinical Homecare Association (2011), as "the provision of medical supplies and/or clinical services directly to patients in the

community.”<sup>843</sup> Many different treatments can be delivered in this way, covering a wide range of conditions and therapy areas. Treatment is delivered and/or administered by an appropriately qualified health care worker/volunteer under the direction of a referring physician, who remains responsible for, and in control of the patient’s care. The provided services may involve medical, psychological or social examination, pain managing, infection education and controlling, physical, speech, or dietary therapy, and empowerment for health promotion and prevention. Home care can also be an essential module of the post-hospitalization recovery plan, particularly when the patient requires assistance. Home health care services must be planned for with organized sets of care to help the elderly receive the needed services while remaining in their own homes. Usually, home health care is more suitable, less expensive, and efficient as standard care in a health care organization, when conducted and managed accurately.<sup>844</sup>

Home health care services are required in today’s social environments, adding to the fact that home is where people wish to be. Since home care is rooted in the private sphere of the home, and care work historically has been construed as “women’s work,” the provision of home care has fallen almost exclusively on women, both as unpaid family members and as formal, paid caretakers. As Holstein argues, it is unjust to allow the care work to fall on women’s shoulders, therefore, there is a need to find other ways of providing caregiving services to elderly people that do not exploit women.<sup>845</sup>

The care received by elderly people today in the Islamic countries cannot be considered excellent.<sup>846</sup> Constant improvement is needed in different spheres, including geriatric services. Even though scientists do not pay enough attention to them, nursing homes were created to improve the quality of life for elderly people. Still, cultural

peculiarities of the Islamic world and the belief in the fact that children should take care of their parents prevents the general population from sending the older people to special facilities. Of course, moral attitudes play a vital role in the lives of all people, but health care professionals encourage everybody to consider one's condition and decide what can improve it.<sup>847</sup> Thus, nursing homes become more popular due to the advantages they provide. The nursing home is an institution where elderly people live and have a particular daily routine.<sup>848</sup> These home-like facilities are preferred by the representatives of the elderly population and by their relatives. They allow patients to be occupied in the activities they prefer, communicate with other people and receive care, which can include treatment.<sup>849</sup>

Nonetheless, many elderly people choose to remain in their homes with their children. Some elderly prefer living with their partners or even alone, which is their right to choose the way to spend their lives. The ability to make choices is one of the aspects of autonomy and dignity. In many countries, however, elderly people tend to be institutionalized in earlier stages even if they are able to function without healthcare professionals' aid.<sup>850</sup> At the same time, obtaining home care can be a beneficial option for many elderly people who do not have severe health conditions. In the UK, people tend to receive this kind of care, and it has proved to be effective, as the elderly who obtain the necessary care remain empowered and autonomous.<sup>851</sup> Their emotional state improves, which positively affects their overall health conditions.<sup>852</sup> One of the desired premises for emotional wellbeing and comfortable living at home is the presence of the partner.<sup>853</sup> During interviews held in Northern Sweden, elderly couples noted that they felt empowered and autonomous as long as they could live together with their partners who supported them and provided the necessary care. When the elderly individual did not have a partner or a close



one, they were likely to make a decision to live in a nursing home, especially when they would develop a serious disorder.<sup>854</sup> Clearly, home care differs from nursing home care in many aspects. First, it provides a significant amount of autonomy to the elderly who can spend their time with their friends or close ones. The elderly do not have to change their routines, which is often the case with nursing homes where a particular schedule is established. The residents obtain the necessary clinical procedures and comprehensive care while those living at home can have regular clinical procedures. They can go to the hospital or receive some procedures at home, which is usually the case.

These two types of care share a lot in common. One of the most evident similarities is that the elderly still receive the necessary care. Healthcare professionals visit the elderly at home regularly or in the case of emergency. These two types of care are also associated with a certain investment into resources. Nursing homes are well-equipped with all the necessary facilities (including medical equipment, furniture and so on). At the same time, home care requires certain preparation as some technologies may enhance older adults' autonomy and sense of dignity.<sup>855</sup> The patient's home should have a convenient means of communication. The elderly should have a telephone, a cell phone and/or laptop to be able to contact (or respond to) a healthcare professional. The ability to call for help can be regarded as one of the tools used to increase autonomy and make sure the patient will be cared for in case of emergency. The elderly person's house should be equipped properly to make it more comfortable. It can be beneficial to have an elevator if the house is multistoried. Such technologies will help the elderly feel less vulnerable and helpless.<sup>856</sup>

It is necessary to add that this approach can be the most appropriate alternative for Islamic countries where home care is seen as the only option. Importantly, people should

understand that elderly people want to be in control of their life, which means they should have an opportunity to address healthcare professionals, rather than go see a doctor when their close ones think it is needed. It is crucial to make sure that the older adults make choices and have the technology to acquire the necessary healthcare aid. Home health care will reduce pressure on family members, many of whom are already balancing fulltime employment and parenting, to act as care providers. It is also the most cost-effective way to increase access to primary health care services for such a vulnerable group.<sup>857</sup> Furthermore, it will help the society to develop awareness on the elderly people's needs and rights. Primary care is an arrangement of operational features, which has been established to respond to the emerging needs of the population. Comprehensive primary health care offers health promotion and preventive measures from which elderly people may benefit in terms of their health and independence. Geriatric evaluation of individual medical, physical and social needs, incorporating isolation and loneliness, have been recognized to be beneficial if it is incorporated in primary health care. Since most people at the end of their life favor to be in their own home, care provided necessitates continuity, coordination and trained health care outreach teams.<sup>858</sup> For many people, the removal from their homes and placement in a long-term-care facility would be the cause of erosion, a great diminishment of their selves, and a loss of self-identity. Feminists and others are correct in thinking that humans have a moral obligation to respond to others when their care providing services provide a morally significant and valuable service.<sup>859</sup> Home care helps the frail, who value their home lives keep their sense of self, retain their self integrity, and helps them hold themselves together for as long as is feasible.<sup>860</sup>

The principal problem that the elderly's services face today is a lack of institutional facilities, which is extremely below population's need. It has been notable that the main problems confronted are the poor environments in these institutions and the lack of skill for the staff. A study conducted in the west of Turkey, showed that elderly people living in a family environment had higher levels of self-assessed quality of life compared to those living in institutions.<sup>861</sup> Another study in a rural area determined that living with family results in higher levels of life satisfaction for elderly people. Therefore, given the deficiencies in these institutions, home care services have an important role to play in resolving this problem. It is important to encourage individuals to remain at home by giving priority to organizations such as 'Care at Home' and 'Daytime Care Homes.' The majority of elderly people in Islamic countries do not have access to geriatric service; geriatrics services in particular are uncommon and, if existed, it is unevenly distributed across the country.<sup>862</sup>

Elderly health problems have been traditionally seen as unexciting and irreversible. The absence, until recently, of a well-defined specialty left the geriatric practice indistinguishable from nursing home care. There was no vision of the challenge of treating and caring for elderly, directing programs of home or community based care, or of pursuing research in geriatrics. There was little awareness of the availability of training programs to students. Actually, postgraduate education, particularly in primary care, should focus on the assessment of complex and often multiple problems in older people and chronic disease management. Preventive care, understanding the usual course of common diseases, can facilitate practical and sustainable chronic care management programs, hopefully to maintain older people in a community setting, avoiding

unnecessary hospital admissions. To this end, it is important for Islamic countries to establish community geriatricians and general practitioners with a special interest in older people. With proper training, these health care workers could easily provide the foundation for older people's health services in a community setting: implementing physical and mental health, and surveillance programs. Certainly, this will require a shift in culture for this group of workers and an ability to manage change.<sup>863</sup> Positive attitudes, absence of stereotyping and providing better learning experiences in educational programs will benefit elderly people who seek health care. It also provides a positive challenge for nursing schools to develop a module of geriatric nursing to satisfy the demand for knowledge and encourage nurses to care for the elderly. While in the West general practice is the cornerstone of care for older people in the community, applying this model in Islamic countries may prove difficult as most general practitioners are in private practice and may not devote time to assess complex geriatric patients. Although older patients present more problems and take longer to give and receive information, the average length of encounters between the doctor and patient declines with the patient's age. A substantial portion of geriatric practice is related to psycho-geriatric problems such as intellectual impairment,<sup>864</sup> dementia and depression. General practitioners and the patient's family presently bear the brunt of providing care without having the appropriate support in the community. There is a dire need for skilled health facilities, residential complexes and agencies for home-based care of these elderly patients. Rehabilitation from the acute illness to help return the older patient to the level of function is often lacking in many hospitals.<sup>865</sup>

### **5.3. Ethics in clinical practice: what works and what doesn't**

Health care professionals frequently face the ethical dilemma of individual best interest, such as moving frail elderly patients to a nursing home, and the personal wishes of remaining in his/her own home with support to maintain their dignity. Thus, by following the codes of ethics and ethical standards of practice, health care providers will be more alert of the prejudices and emotional reaction, thus more capable of making decisions based on reasonable facts rather than naive emotion. For instance, a physician who has a keen desire for patient safety may advocate for institutionalization rather than exploring different in-home services and housing substitutes that may let the patient stay in the society. In fact, the physician is required to use the plan designed with the least restrictive and least humiliating involvement for the elderly individual. This approach can reduce harm for both the older individual and the physician. A standard in assessing the plan of action is whether the intervention is fair, appropriate, and respectful. Furthermore, physicians cannot determine these ethical issues in isolation; organizations need to build learning and guiding procedures that will help health care providers to examine the feeling of uncertainty and professional vulnerability. Home-and community-based organizations should also have a formalized volunteer ethics committee, where practitioners can present illustrations of complicated cases. The committee might consist of various internal workers and administrators, as well as community members. It is always helpful to have a myriad of perspectives represented, and participants can include practitioners, supervisors, community members, physicians, psychiatrists, clergy, attorneys, philosophers, and, of course, ethicist. Some organizations also have less formal “ethics brown bag sessions,” which can be held during lunchtime. Workers can discuss

ethical concerns with colleagues and an ethicist. Brown bag lunches usually occur more frequently than ethics committee meetings so cases can be discussed with members and trained ethicists in a suitable manner.<sup>866</sup>

In many Muslim regions, most of the patients with life-threatening diseases (e.g. tumors) get treatment when the disease is in its late stages and incurable. Patients with such terminal diseases are expected to die in their own home; the impression is that the incurable patient can bear their suffering better when he/she is at home. This viewpoint is associated with uncertain outcomes, especially when hospitals are advanced in medicine and technology. When a hospital discharges a patient with a terminal disease or who needs intensive continuous care, in general, it means withdrawing direct care by health care providers and hospital equipment, and also places a substantial burden on the families that are not capable of providing continuous care. For example, in Tunisia some people verify that the common fear amongst physicians is the family's reaction to death, especially with women. This can involve yelling, collapsing, panicking, etc. Physicians attempt to do discharge and persuade the families to take the dying patient home, to avoid these reactions and the humiliation without any attention to patient wishes. In fact, this approach appears to be supported by Ruling 1634 of November 1981, article. 24, which permits moving a terminal ill patient to his home if he or the family requested so.<sup>867</sup>

The literature demonstrates the complexity of ensuring that elderly people residing in nursing homes enjoy a good quality of life. Thus, to achieve an optimal quality of life for the elderly, a consistent theme is needed to ensure that nursing care is customized to individual needs. The first theme is concerning the *environment of care* that arranges the setting in which care is provided, to assure that patients are treated with

dignity. The environment of care, mainly the physical environment, incorporates privacy issues and the nature of the organization.<sup>868</sup> By way of a social contract, the feeling that the consumers of a service are important people will overcome difficulty to guarantee the accommodation is of pleasant quality. On the other hand, a substandard environment of care indicates a failure to acknowledge the value and dignity of the patient or service user. Lack of privacy for assessments, inadequate access to toilets, mixed gender wards, and cruel accommodations would compromise basic human dignity or *Menschenwürde* and dignity of identity.<sup>869,870</sup> Furthermore, Mann outlines that violations of personal privacy and humiliation are dignity violations.<sup>871</sup>

The second theme is about *staff attitudes and behaviors*. This involves, a lack of respect, intolerance, impatience, and arrogant. Patients feel that the care accorded to dignity when it includes an appropriate language, compassion, and kindness, time and care is spent in helping people to dress and eat appropriately, and when communication is improved to ease patient-centered care. This also was an active subject in the *Dignity and Older Europeans Project*, where elderly individuals stressed the importance of exhibiting respect and gratitude by care providers.<sup>872</sup> From a theoretical perspective this also would seem to reflect *Menschenwürde* and dignity of identity. Dignity of identity and self respect are violated by behavior that is disrespectful of dignity because such behavior results in loss of self respect, low self esteem, and feelings of unworthiness. In fact, the term nursing means nurturing or nourishing and to nurse someone means to identify and respond to rights of worth. This also matches Mann's claims that not being seen, or being seen but only as stereotypical member of a group.<sup>873</sup> However, group categorization can be either a fountain of pride or a sort of dignity violation. Being seen only as a group

member can be judgmental and depersonalizing, which lessens the individual's dignity.<sup>874</sup>

*The third theme is culture of care* that involves the common beliefs and values about the nature approach and organization of care that may dominate in an area; it is also referred to as "Ward Philosophy."<sup>875</sup> For example, for a patient with dementia, the event could involve financial limitation, prioritizing the institutional objectives over the needs of patients, discharging patients quickly, staffing arrangements, such as many different nurses caring for the patient over any given period, etc. These are examples of care that require dignity. As a matter of fact, elderly people want to exhibit their autonomy, to be involved in their care, to be free to accept or deny medical treatment, and to be treated as human beings in an environment that respected cultural difference and privacy. If the culture of care is positive and focused on therapeutic objectives and patient well-being then any complaints processed will be assessed in beneficial scales, such as the availability of advocacy services. Culture of care appears to represent dignity of identity, and failure to provide holistic and individualized care applies to Menschenwürde and to dignity of identity. Moreover, a study in the prevention of abuse and neglect in elderly care reveals that elderly patients frequently complain of complexity in acute hospital wards, and the inaccessibility of health care providers. According to Morris, hospital wards were not a suitable place to care for elderly, and this problem is very important because elderly account for most hospital users.<sup>876</sup>

The final theme is the *specific care activities* that either promote dignity or obstruct it, for instance, bathing, toileting, eating, and so on. In this setting the application to Menschenwürde would be, as depriving conscious or unconscious patients of adequate privacy or care for hygiene, feeding, etc., appears to be a violation of human dignity.<sup>877</sup>



Nevertheless, if an elderly person decides to disregard usual standards of cleanliness and bath, an attention of his best interests will have to balance the value of his autonomy and independence against the risks of self-neglect, the suffering caused to his dignity and others.

The issue of autonomy in home health care can arise in regard to even the most mundane matters. Loss of autonomy in particular may arise when a doctor recommends a restricted diet and the attendant feels constrained to follow the doctor's orders. When the recipient is dependent on the attendant for shopping as well, autonomy and choice may be even more restricted. The recipient may lose control over the ability to purchase and consume favored foods, or snacks, or other items. The attendant controls the selection and preparation of foods. Also, the eating time might be an issue; for instance, a carer may have preferences or schedule demands which may take precedence over the patients' preference as to when to eat. Dependency for bathing also raises the question of whether the recipient has control over when, or whether the preferences and schedule demands of the carer take precedence. The care receiver may prefer to watch a favorite TV show, listen to a game, read, or sit in a garden at the time that carer has scheduled something else. The issue of autonomy also arises in regard to the care receiver's control over medical care and treatment. Therapy and exercise schedules raise the question of control over the time of the treatment and whether the preferences and convenience of the provider or the recipient take precedence. The question of whether the care receiver will be allowed to choose to reject medical treatments or medications also arises. Rejection of services often leads to doubts about the care receiver's mental competence, particularly where traditional medical treatment is involved. These doubts may lead to further loss of

autonomy and control for the recipient. A recipient may also be restrained from taking actions thought harmful to him or her.<sup>878</sup> At the end, the concept of dignity demands an acknowledgement of worth and a related expectation that people should be treated with respect for their value as humans. In order to provide a dignified health care practice, physicians and nurses need to focus on the four themes (environment of care; staff attitudes and behavior; culture of care; and specific care activities).

Autonomy ultimately involves more than just the question of whether the care receiver can control details of care or reject care. Autonomy involves a positive, as well as, a negative dimension.<sup>879,880</sup> The positive dimension would require a focus on providing services to enhance the recipient's ability to interact with family, neighbors, and friends, and to participate in community activities, or other social events. It would require greater control by the recipient over transportation services, perhaps requiring family, neighbors, or friends to be brought to the recipient. It would also require scheduling other services around these activities based on the preferences of the recipient.<sup>881</sup> The carer may also have to follow the recipient and assist him or her in participating in outside activities.

According to Parks and Wick, the principle of autonomy is arguably of little use when we are considering people of advanced age, who cannot maintain the façade of being independent and self-sufficient. The principle, though, is not helpful within the context that a large number of elderly people find themselves; in nursing homes or assisted-living centers.<sup>882</sup> As Agich points out, the conditions of old age and the living conditions one finds in long-term care facilities are not conducive to the principle of autonomy, as it has traditionally been understood. Thus, there is a need for

reconsideration of autonomy, how people understand it, and the ways in which it applies to elderly people, to ensure that those in long-term care facilities are not harmed by it.<sup>883</sup>

Yet, to speak of autonomy in home health care may seem anomalous because recipients are physically and sometimes mentally disabled and cannot perform some of the basic activities of daily living. However, physical disability and dysfunction, even partial mental disability, do not mean that the recipient has no preferences regarding any aspect of his/her life, or no desire to exercise any control over some or all of those aspects. A study of home attendant services in New York City revealed that about 90 percent of recipients were sometimes able to give directions to the home carer regarding their care, and over 70 percent were at least sometimes able to manage their affairs.<sup>884</sup> Numerous studies have attested that a loss of autonomy by the elderly can negatively affect their emotional, physical, and behavioral well-being, and ultimately undermine their health over the long run.<sup>885</sup>

Given the range of threats to personal identity, which are posed by the care home environment, this chapter would be incomplete without a brief consideration of the alternatives to nursing and residential home care. Kane et al., for example, report an evaluation of an adult foster scheme in the United States, which suggests that foster care compares favorably with nursing home care in relation to quality of life and cost. Adult foster care homes are private residences. Meals are served with residents and staff eating together and routines are kept to a minimum. The resident manager provides personal care and housekeeping. If necessary other services, such as skilled nursing, can be bought in from home health agencies. In a large study between residents of nursing homes, and

foster care residents reported that the elderly are having more social activity, even when controlled for disability.<sup>886</sup>

To sum up, factors considered important included a homelike atmosphere, having a safe supervised place to live, personal assistance, privacy, access to medical care and flexible routines. This type of care provision seems to offer a mainstream alternative to nursing homes. Retirement communities for independent older people, popular in the United States, offer access to 24-hour emergency assistance and companionship through planned activities.<sup>887</sup> A number of these facilities have added assisted living facilities allowing older residents to age in place. There are similarities with the system of service houses in the Scandinavian countries, which provide care for disabled people with care needs from moderate to severe.<sup>888</sup> Older people can move into the service house while still relatively independent and can negotiate an increase in the level of service as their need for care increases.<sup>889</sup>

### **5.3.1. A new look at ethics in the home, institutions, and community**

A new look at ethics gave the caregivers a chance to support the elderly and show that they respect their privacy even though some were not able to cope with simple activities and required assistance in bathing, feeding, etc. According to the latest advances in geriatric medicine, caregivers should make sure that the patient feels autonomous and dignified. Although some procedures may be associated with complete dependence and the absence of autonomy, it is a caregiver's job to make the patient feel that the procedure is routine and has nothing to do with restricting the patient's autonomy. For instance, the caregiver should explain that helping with such activities as bathing is nothing but a procedure related to

hygiene. At that, the caregiver should make sure that the patients do everything they can on their own and the caregiver steps in when the assistance is really required.<sup>890</sup> Due to the changes in this sphere of health care, the relationship between the caregivers and clients started to be emphasized in the majority of facilities. The plans targeted at its improvement were designed on the basis of information received from the agencies, relatives and older people. In this way, another point of view became the basis for the new approach of caring. It widened the scope of ethics adding new aspects. The professionals were suggested to develop several significant skills, “attentiveness, clear and gentle communication, and appropriate responsiveness.”<sup>891</sup> The changes were implemented in various facilities, and professionals providing home care and daily services emphasized that the mentioned earlier features should not be neglected in community-based long-term care. As the information was gained from the stories told by the individuals who were close to the involved subject, and the plans designed on its basis were likely to be useful in practice.

Except for the new everyday ethics, the ways of solving ethical dilemmas was discussed by the scientists. They tried to provide the best guideline for decision-making managed by both individuals and society. The influence of such things as ageism on this process was underlined along with other issues, such as paternalism. Roy states the way the aging concept is perceived has an impact on the provision of care services.<sup>892</sup> Moreover, Wilmoth and Ferraro also considered them in their work, which proves that they are very influential and provide an adverse effect on the individuals.<sup>893</sup> The concepts of autonomy and dignity are too broad and abstract to be clearly understood from the very beginning when they deal with the older people. It is normal that people cannot realize how their views on the same situation differ. Thus, when defining the major issues of caregiving, specialists

gain an opportunity to make the first step forward and find out what can be done to improve the situation.

In hospital care, the patient is a guest for a short-term enclosed by unknown climate, and advanced technology, that make him/her feel confused and alienated by the care received by physicians and nurses whom they may have never met before. It is perhaps natural then that the ethics of the hospital are primarily concerned with bolstering patient autonomy, since patient autonomy is challenged or eroded from numerous directions. In the nursing home, most of the everyday ethics have more to do with individual autonomy in the face of congregate living arrangements, which necessarily compromise individual freedoms. But the home is where the resident is king or queen. It is where people feel most comfortable, most secure in exerting their individual autonomy. Autonomy, therefore, may not require quite as much bolstering as in the acute-care or even long-term-care institutional setting. The recipients of home care services are not fully independent; they are most likely frail and in some way dependent. Hence, a home care ethics will have to be sensitive to the ways in which autonomy is or is not challenged in its setting.<sup>894</sup>

Moreover, emphasizing the need of attaining a better balance between care and cure doesn't mean to reduce the significance of technological advances on the elderly health. Therapeutic science should upsurge its knowledge of the biology of aging; some of that knowledge will create beneficial high-tech usages for the alleviation of suffering and disease. Concurrently, a continuance of a robust and important modern development in the medical treatment of the elderly will be bound. Technologies to simplify home care services are one of the current developments, as it involves assessments and processes that are similar to clinics and hospitals. They have the potential to reduce pressures on

family and the costs of services. In fact, promoting geriatric education and training for health care providers, would make a significant impact on improving the care of the elderly. The traditional moral obligations to the elderly have been interchanged over several generations. The simple idea is that the elderly people have responsibilities toward the health of the young, in turn; the younger have responsibilities toward the health of the elderly. The perception of appreciation within families has been an important balance or foundation for obligation. Hence, with the changing conditions and dependency status of people's lives, it is rational to be ready to provide resources for each other as needed.<sup>895</sup> However, this cultural interchange on generations' obligation is critical; it is not easy anymore to grant the moral traditions of exchange.

The health services need to develop residential accommodations; home help facility, meals-on-wheels, day centers, laundry service for the incontinent, night assistants, and safety amenities for the physically injured. Elderly patients should have access to the rehabilitation programs, including physical treatments, family counseling, support, and training of caregivers in the basic components of home care. The lack of specialist geriatric services does not mean that the elderly are not receiving the services they need. It may well be that the close family network obviates the need for a traditional Western geriatric service.<sup>896</sup> There is now an emerging consensus for a more holistic approach. Incorporating the assessment of physical and social functioning, as well as, the assessment of economic and environmental resources, since these place constraints on the options for intervention.<sup>897</sup> There is also an urgent need for upgrading the extent and quality of services for the aged currently provided through primary health care. The primary care physician is having an outstanding position to begin and supervise this kind

of care.<sup>898,899</sup> The other primary health care team members such as nurses, physical therapists, and nursing aids, besides volunteers may be effectively used in such programs.<sup>900</sup>

### **5.3.2. Raising standards: educations, and attitudes through training**

Progress and science never stayed apart for a long time, which can be seen on the example of geriatric medicine. Its objectives changed with the course of time, which was done with the help of research. One of them implemented a new image of ethics of caring for elderly people, and the professionals needed to continue their education to obtain a new set of knowledge. One of the most significant issues associated with nursing homes is the lack of privacy.<sup>901</sup> Another issue is concerned with the lack of autonomy when it comes to treatment, as patients often have no ability to affect the treatment developed. The written consent is seen as one of the possible solutions to the problem as patients of nursing homes understand the benefits of each procedure and feel safer, as well as, empowered since they may question some procedures (if their mental health is not impaired).<sup>902</sup> The problem of the lack of knowledge or skills is considered to be the main one, and to solve it; the staff receives special training.<sup>903</sup>

The majority of elderly people are claimed to have several health problems. This condition makes them search for health care in order to improve the situation. It proves that geriatric medicine and its quality are vital for the elderly. Researchers underline that all health care services for such populations should be not only well organized but also based on ethical concepts.<sup>904</sup> Unfortunately, the quality of medical education in many Islamic and Arab countries is not good enough. Schools do not offer the mentioned specialty, which



makes it impossible to choose it. As a result, that little amount of geriatricians that provide their services in the country receives education and training abroad. Such difficulties have an adverse impact on the sphere of health care and on the patient's condition. It is rather hard for many people to leave their motherland for several years. Thus, the number of specialists is not enough to deal with the whole population. Other medical professionals, who work with the elderly, often lack needed skills and knowledge, which affects people's health adversely.

Knowing that such situations are common for many countries, the government in the US established new infrastructures. Thus, people received professional training to meet the needs of health care staff in foreign countries and contribute to the development of their communities.<sup>905</sup> However, Nordenfelt claims that the majority of the professionals who look after the elderly have never had adequate training for their job even though they received education and worked in developed and rich countries.<sup>906</sup> The author also mentions the opposite opinion of his colleague who stated that care for an elderly individual is mistakenly regarded as rather basic. It is often believed that older people who do not have severe health conditions do not need any specific treatment, and anyone without special skills can care for the elderly.<sup>907</sup> Still, on the basis of this paper, it can be claimed that the first view is the right one, as it was proved that even routine actions, such as greeting, that are done in different manners are likely to change the way the older see themselves and build relations with caregivers.

With the help of training, the members of the staff enhance their knowledge and start considering the same situation from different perspectives. In this way, their attitudes also change.<sup>908</sup> Previously, patients and their caregivers could not find a common language and

considered the same situation in different ways, but today the professionals gain an opportunity to let them know how their actions affect the lives of the elderly population, their mental state and the way they see themselves. The caregivers tend to become more engaged due to the training they receive.<sup>909</sup> Such qualities may be less critical if the professional works with the general population, but when dealing with the elderly, they are extremely vital.

As a matter of fact, the improvement of everyday ethics led to the alterations in the standards of education. Still, many professionals claim that caregivers do not receive adequate training in many countries even now. In Islamic countries, families mainly hire a carer for their elderly member from a foreign country, who has no training or skill on caring for the old, and who speak a different language. As a result, there is a lack of specialists who are able to provide the elderly with decent care. When interacting with the elderly, caregivers are encouraged to be respectful and involved. They should control the situation but let the patient make one's own decisions at the same time. It is critical to remain patient and attentive, as the elderly require normal treatment even though they are not able to manage their lives without support. So caregivers should do their best to build trustful relations and find a common language with their patients.

Indeed, Community Health Nursing (CHNs) is stimulated to apply a decision-making scheme, beside the nursing procedure in their practice. When institutionalization of an elderly individual is being measured, the CHN requires identifying patient preferences and definition of health. This should be the first step, followed by the risk and benefits of such a decision.<sup>910</sup> Furthermore, forming and supporting countrywide bioethics webs in alliance with religious specialists, physicians, theorists, legal specialists, sociologists and

other observant philosophers would be beneficial. Similarly, expanding collaboration of medicine, religion, ethics and law necessitates better understanding and evaluation of medical ethics subjects and the strategy of traditional adapted solutions. In the long run, academic training will need to guarantee that all physicians are experienced to work in a holistic, compassionate, and multidisciplinary manner that respects the dignity of patients.<sup>911</sup>

Health care ethics goal is to assure that patients are treated with dignity and respect in health care practices. This model is affirmed in policies supporting patient autonomy. Modern bioethics believes that respect for autonomy is fundamental when people make decisions for themselves without an unjustifiable affect from others. The essence of dignity and respect for age is an influential matter.<sup>912</sup> Therefore, in Islamic countries, education for the care of elderly people and its effect on practice recommends evaluation and measurements of the elderly needs. Ongoing nursing education has been found out to have numerous positive results with improving care planning,<sup>913</sup> the natural collaboration between members, better autonomy and confidence,<sup>914,915</sup> and personal and professional development. The principle of respect for autonomy has seen more support by respecting the elderly preferences, and by the way health care professionals examine and treat elderly people.<sup>916,917</sup> Furthermore, experimental studies submit that individual autonomy has a special value to elderly people in continuing care situations.<sup>918,919,920</sup> In addition, these studies recommend that a feeling of being autonomous, respected and valued is fundamental to the experience of a worthy life for elderly people.

The stereotyping of aging continues to exist in society and health care workers remain vulnerable to ageist views due to their high contact to elderly individuals with illnesses.<sup>921</sup> Despite the arguments to correct the attitudes toward elderly individuals as

one homogenous group, there is an urgent need for attentive continuous education to battle the stereotyping views and negative attitudes toward elderly. Early contact of healthy elderly people by students is recommended to improve their attitudes toward the elderly people.<sup>922</sup> As a matter of fact, with today's health care market competitiveness and development, care providers should start to see their elderly patients as customers who need satisfying services rather than dependent receivers of care. Educational programs in hospitals, which emphasize on service-oriented function and improving patient results, are needed. Also, these programs should permit time for health care providers to assess their belief and compare it with societal attitudes perceptions and attitudes toward the elderly. A study in societal impacts of ageism demonstrates that education can certainly decrease the negative views on aging. It was showed that giving knowledge on age and interaction with elderly people to children, have improved future attitudes toward elderly people.<sup>923</sup> Hence, examining the cases of an existing appropriate practice and categorize features that can be widespread to health care services universally, and recording positive observations made by elderly people and their caregivers on the received care will formulate components of service plan that grant elderly individuals to feel that their dignity and autonomy are reserved.

Suggestions for resolving the dilemmas generally take the form of better understanding the individual or framing the issues, consultation with a supervisor or ethicist, or use of case conferences or interdisciplinary team meetings. Values history enables families and professionals to better understand the individual.<sup>924</sup> They do this by explaining underlying life values and personal perspectives across a whole range of care issues. The National Values History Project developed and tested a values history inventory that has

been widely disseminated and translated into many languages. It is divided into several sections and includes questions on attitudes regarding independence, control, personal relations, and illness and dying.<sup>925</sup>

Ultimately, the training of health personnel in geriatrics and care of the elderly is critical as an important first step toward the development of the services, which will ultimately be needed. To cope with the increasing elderly population, a graduate training program in basic geriatrics and care of the aged should be provided to the medical, nursing, and allied health personnel. In this program, emphasis should be given to a multi-skill approach, rather than specialization. According to a study survey in Saudi Arabia, there is now scope for the creation of adequately resourced academic units in general teaching hospitals to provide acute geriatric assessment, rehabilitation, and coordination of long-term care for elderly patients. Such units will provide leadership, act as training centers, conduct research and evaluation in clinical geriatrics, and ultimately provide the model for the further development of geriatric services throughout the country. The eventual emergence of geriatric medicine as a recognized specialty in hospital practice and the creation of departments for the care of the elderly, in general acute hospitals, will then expand as the need for it develops, based upon the groundwork and experience of the teaching units.<sup>926</sup> The study highlights the importance of health care providers to understand the physical and psychological changes of ageing to provide good care for elderly individuals. Generally, gerontology content is taught as a subtopic of other courses (medical, surgical, community health), and nursing students obtain clinical experiences about older patients care through hospital rotations, in aged care homes, and primary health care facilities.<sup>927</sup> Lack of leadership and role modeling,

together with under-resourced physical environments and inadequate education were significant barriers to integrating gerontological content into academic nursing curriculum.<sup>928</sup> These barriers lead to graduating with no experience and knowledge about geriatrics. More emphasis on gerontological curricula and training programs are strongly needed. Furthermore, nurse educators should consider restructuring nursing curricula in Islamic countries so that integration of aspects related to nursing older people takes place early in an educational career.<sup>929</sup>

#### **5.4. Conclusion**

The 21<sup>st</sup> century is known for the tendency to improve various spheres of life. Due to the advances in healthcare and technology, it became the time of global demographic transition. The elder population is claimed to increase every year so that it will number more than one-fifth of the whole population in less than 40 years.<sup>930</sup> Realizing that elderly people often require more care and support than the general adult population, scientists and practitioners all over the world started to actively consider how the quality of life of elderly people can be improved in the 21<sup>st</sup> century. Such an approach arose in the West but soon it spread worldwide and remains advantageous even today. Still, in many countries, such as Islamic ones, the population tends to believe that the families are fully responsible for caring for their grandparents. Their religion and moral views seem to be opposite to those accepted in the West. This chapter provides a detailed analysis of the approaches to geriatrics existing in the West, as well as, the Islamic world. The discussion above provides insights to a particular aspect of the problem. Thus, in “The Support of How Respecting Human Dignity and Personal Autonomy Can Help to Improve Elderly Health Care in Islamic Countries”,

the patient-based approach and its use in both Western and Islamic countries are examined. It is clear that the majority of countries across the globe have adopted this paradigm, which involved a particular attention to caregivers' responsibility to enhance respect for autonomy and the sense of dignity in the elderly. This paradigm is evident in both home and nursing home care. It can be concluded that home care is beneficial for older adults who do not need intensive care while nursing homes can be the only option for people with severe health conditions.

In "Ethics in Clinical Practice: What Works and What Doesn't", various ethical issues are discussed. Specific attention is paid to education and training. It is possible to conclude that ethical values are similar in Western, as well as, Islamic cultures. Younger generations understand that they are obliged to create proper conditions for the elderly who deserve proper and respectful treatment. They also understand that older adults have the right to remain autonomous and have a high sense of dignity. Unfortunately, these values are often neglected when people face the need to provide care to the elderly members of their family. Professionals are trained to provide high-quality services and develop an ethical conduct towards patients. It is also clear that people may need to obtain some training, especially when it comes to home care. They should actually understand how to ensure respect for the elderly people's autonomy to maintain their dignity later in life. It is vital to understand that professional caregivers receive special training and education, which allow them to bring the most benefit to the elderly. Thus, when the family refers to them, it gives the older relative an opportunity to be healthier and live happier.

The analysis implemented helps understand the major opportunities for and barriers to successful shift in the Islamic populations in regards to nursing homes and home care and

the overall process of aging. It has been acknowledged that the quality of life of the elderly improves greatly when the caregivers promote their dignity and autonomy.<sup>931</sup> The Islamic countries lack the focus on this sphere of the human life. However, it is vital for the successful development of the society. The Quran emphasizes the vitality of respectful treatment when dealing with the elderly population.<sup>932</sup> At the same time, religious leaders should not be the only source of knowledge on the matter. The government should take up more responsibilities. It is clear that the government should allocate more funds to develop a network of nursing homes where high-quality services will be provided. Significant attention should also be placed on educational establishments that will train professionals in the sphere of geriatrics. Finally, media can also play an important role in the process as they can educate people in regards to the benefits of nursing homes and home care. The media can start the ongoing debate in the society that will eventually lead to the shift in the Islamic societies, and the elderly will have access to a truly comprehensive care that will address their physical, psychological and emotional needs.

Caregivers were always taught to focus on the patients and their needs. When the ethics of caring for the elderly improve with the help of new home and community based services for elders that put an emphasis on dignity and autonomy, it will positively influence the overall health condition.<sup>933</sup> As it turned out, the interaction between the professional and patient plays a critical role in the outcomes of care delivery. The caregivers can provide the elderly with an opportunity to make their own decisions regarding clothing, eating, and going to bed, etc. These ordinary activities make the patients feel they have enough power to control their lives.



Apart from creating the necessary premise for the physical and emotional health of the elderly, it is important to understand that ensuring dignity and respect for elderly autonomy will maintain the balance within the society. The older generation receives respect and the ability to live a dignified life while the younger generation develops a firm belief that they should contribute more to the community that will later give back in the form of care when they are old. This balance can be easily kept as it is based on the major values of humanity. Overall, the main goal of elderly care programs is to keep the elderly people in their preferred environment.<sup>934</sup> Thus, promoting a meaningful life is particularly important due to the increasing facts that too many elderly living in institutions or in their own homes, experience a sense of an unworthy life; an intuition that their individual worth has ended.<sup>935</sup> Consequently, adopting a fresh perception on an analytical gerontology and a respected devoted approach that aims to comprehend ageing process and requirements to change for the better is needed.

A particular challenge in Islamic countries health care is to transform traditional well-being arrangements centered on dependency and to discuss the experiential uncertainties that are associated with ageing, for the sake of helping elderly people preserve a practical and sustainable identity.<sup>936,937</sup> This chapter considered the support and motivation for communications between health care professionals, elderly people, and their family as a vital approach for individual's well-being. Others see technology as empowering in broadening the horizons for older people by increasing their sense of control and empowering them to make choices, as well as, providing avenues for wider social contact.<sup>938</sup> As Bernard and Phillips suggest, the potential applications of technology are extensive and this is one area in which the quality of life for frail older

people could be significantly improved.<sup>939</sup> Ultimately, a loss of identity has been known as one of the utmost harmful effects of illness and infirmity. Therefore, reconstructing a new and equally valued identity is a vital mission in adjusting to chronic disease.<sup>940,941,942</sup>

However, patient autonomy should probably play a greater role in home health care, as opposed to less. The choices in home health care are more subjective and personal, involving more private matters. The treatment is for a longer term and often permanent, and therefore loss of autonomy and control will be a much greater burden on the life of the patient than in a short-term, acute care setting. Finally, in home health care the providers are guests in the patient's home, where the patient has a legitimate interest in maintaining control and autonomy. In acute care facilities, by contrast, the patient is a guest in the provider's facility and can legitimately be asked to accommodate the practical needs of the provider's operations.<sup>943</sup> In many societies, loss of autonomy and institutionalization are commonly the outcomes of the devaluing of the elderly. Advocacy is almost a new function for nurses caring for elderly individuals. It is the advocate role that gives nurses the chance and responsibility to support and protect the elderly's autonomy. Advocating for autonomy include providing options for elderly people about their identity, life-style, living arrangements, independence and privacy for as long as possible.<sup>944</sup>

The negligence of the emergent difficulties of elderly health care can be connected to the difficulty all civilizations have in coping with future problems; they repeatedly get ignored in favor of more immediate catastrophes. However, they are near and real. The more they are pushed a side, the more problematic they will be to deal with.

Governments, health care organizations, health professionals, and communities can all be blamed for delivering poor service to elderly patients, and they will be doing themselves damage in their own old age.<sup>945</sup> Therefore, there is a strong demand to provide acceptable and suitable health care facilities tailored to the elderly's needs, and to review and reconsider the traditional moral practices and actions.

The elderly have low expectations of functional recovery from severe illnesses, and their families often provide them the informal care. This may encourage an unnecessary state of dependency. Secondly, the family provides informal care in the way they think fit, which may lead to inadvertent neglect or overprotection and inappropriate caring attitudes. Thirdly, lack of understanding of the special needs of the older patient may lead the treating physician to assume an early discharge, and recover at home is more appropriate for the patient. This can impact the family who may have to give up a job to assume the role of carer. There are many issues and challenges that face geriatric services in many Islamic countries including the recruitment, development and retention of medical staff. Having enough clinical leaders who can work with other professionals to develop an integrated approach to care for the elderly is surely the way forward to resolve many of these issues. Islamic countries should be able to look to the Western countries provide training/support opportunities for aged care workers including the training of future geriatricians. Providing an answer to all the challenges should incorporate the best aspects of the many models of healthcare delivery in the developed world. To use a one-model fit all approach (i.e. whatever suits the West would also suit Islamic countries) will be neither practical nor sensible. However, Islamic countries see a rising number of older

people, and will need to swiftly develop systems to cope with it, while at the same time recognizing factors that will influence future health care needs.

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## **Chapter 6: Conclusion**

This study has started with the hope to get a better understanding of old age and the health care of elderly people in Islamic countries. Since old age is a noticeable phase of human life, it makes sense to consider the distinct purposes and obligations that define it and the connection of these purposes and obligations to the other phases of a person's life. The study has focused on describing and classifying dignity, and respect for autonomy and the necessary steps towards awareness of the way elderly people are cared for. Respect for dignity emphasizes the need to reconsider and expand the larger catalog of health, meaning that an awareness of dignity may help elucidate a remarkable phenomenon in medical care. One of the important understandings that came out of this study was how the image of old age is rooted and entangled within societies. The negative picture and neglect of the needs of the elderly as human beings and an aging group have resulted in consequences that badly affect their treatment, their health, and their wishes in life. A loss of identity has long been known as one of the utmost harmful effects of illness and infirmity. Therefore, reconstructing a new and equally valued dignity and identity is a vital mission essential in adjusting to chronic disease. In many Western countries, the attitudes towards aging have received a great amount of attention and consideration in research, education and training, which lately have been successfully addressing and solving several challenges associated with elderly care.

Several examples of the current approach to caring for the elderly were discussed in the chapters, showing that it is not yet possible to make definitive, quantitative statements about what appears to be a tangled connection between dignity and health. However, the discussion makes it evident that dignity is of fundamental importance for determinations to

promote and protect individual autonomy, with respect as the key to describe dignity. Human rights can only become meaningful when people grant to others the dignity they assume for themselves. In health practice, awareness of the personal and societal importance of dignity can be translated into concrete action at an individual, community, and institutional level. People can promote and protect dignity within their own spheres of activity and influence by being aware of the various forms and expressions of dignity violation, such as not respecting individual identity, invading an individual's personal space, and humiliating the individual.

The five chapters presented here are devoted to shedding light on the importance of the application of both concepts of dignity and respect for autonomy to improve elderly health care in Islamic countries. The topic of the elderly health support, in general, was not fundamentally an issue for discussion in most of the Islamic countries. However, the Islamic countries are witnessing an increase in the numbers of their elderly population. As has been discussed in this paper, Islamic religion dictates that the elderly are generally highly respected and that their care is the responsibility of the extended family. But an important consequence of the increasing pressures of modernization and urbanization is a change in family formation, and social attitudes and behaviors toward older people. The traditional family support system in Islamic countries is shrinking, even with the heavy influence of strong connections to Islam and the traditional culture. The family support for elders has also placed many current and future elderly individuals at risk. In a closed culture of paternalism, patient communication is too often left to the physician and families. This approach leads to the growth of concerns about ethics in health care and helps the health professions to focus on the elderly patients' dignity and

growing self-determination. Ethics reflect the part of the everyday world in which people live, work, and serve each other. It is a part of all of people's actions, involving how people show care and respect to each other, and how they engage in relationships with each other. According to the Islamic standard, ethical health is part of general health; thus good character leads to good health.<sup>946</sup> In health care practice, both concepts are often neglected, not intentionally, but because the unconscious rules, which govern dealings with sick people, are inappropriately applied to aging and may motivate unethical judgments in health professionals' choices.<sup>947</sup>

A typical family's approach to caring for their elderly members tends to seize power and dignity from old people. Ordinarily, in many societies, severe sickness involves a suspension of responsibilities, a right to the extraordinary care of others, and an imperative to do everything to get better. Aging is a chronic and inescapable condition. People feel bitterness, frustration and anger about aging, because care is given at least implicitly under the impression that other conditions of the sick role fit the situation. But they cannot. In any given health crisis, only a minimal possibility of returning to an earlier level of responsibility exists. With the thrust of the aging process toward deterioration, loss is inevitable. Dignity for the aged demands that the health and social category of elderly care is mistaken by applying the sick role to aging, and this attitude needs to be corrected.<sup>948</sup> *Caring* for elderly people in states of deep vulnerability demands deep sensitivity, wise perceptions, responsiveness, and knowledge that is highly particular and familiar to individuals. This discussion suggests the need for understanding the multiple ways in which negative ageism penetrates people thinking and behaviors. Thus, rather than stigmatizing people because they seek medical care for forms of suffering that medicine cannot see and



which do not fit into the existing biomedical lexicon, acknowledging that categories of health are themselves too narrow to recognize certain forms of suffering will be important. Future health professionals may look back at the current limited and narrow understanding of health and wonder how this lack of perception could have happened, how they could have missed seeing violations of dignity as sources of injury to their patients' well-being. More importantly, they should contemplate how they could have missed acknowledging methods of strengthening dignity as one of their key therapeutic avenues in these types of situations. The professional/patient relationship needs to be based on a partnership rather than on old-fashioned paternalism, and the arguments provided stress the importance of involving elderly patients, wherever possible, in decisions about their treatment and care.

The first chapter presented information on the globally rising numbers of elderly populations, specifically within Islamic countries. The focus has been on the ethical challenges that are associated with elderly care, specifically concerning the concepts of dignity and respect for autonomy. The literature provides information on bioethics and aging, both in the past and today, to understand how both concepts developed through history, and how old age has become somewhat different than it was in the past. Today, being old does not merely present issues of physical survival. Improved human longevity means that today, old age has established a distinctive and lengthy life phase for which the demands of purpose and the individual's role in health and society must be met.

The second chapter introduced the history of Islamic law and bioethics, and the law's resources in caring for the elderly. As has been examined in the paper, religious approaches to bioethics begin with the belief that a greater power and a set of religious texts govern the parameters for human action. Indeed, religion is important to many

individuals' beliefs and values. The concept of dignity and the ethical principle of respect for autonomy still need to find their place within the general principles of Muslim law (Sharia). The principle of respect for autonomy barely exists; it has been viewed as familial and societal respect rather than as an individual one, which is completely different than the way it should be, and has been declared by many universal organizations to be treated with dignity and respect. Teachings prescribed in the Quran are introduced with gratitude and respect towards parents. Thus, as it has been recognized in Islamic teaching to respect and care for parent and elderly people, these principles should be recognized as well in health care practice. However, a lack of cultural awareness and a lack of proper interpretation of both concepts of dignity and respect for autonomy interfere with the practical application of these concepts. Health care providers and societies in Islamic countries need to implement a strong elderly health support system that can maintain elderly people's dignity and respect for their autonomy, which consequently will meet their needs and improve their health status.

The third chapter studied the history of dignity and respect for autonomy in health care and the difficulty in applying both concepts in health care practice. The different meanings of dignity are defined, demonstrating how inherent dignity is attached to all human beings, and how its value cannot be gained or taken away. The concept of moral dignity is related to the principle of respect for autonomy. It appears in its relation to the individual's behavior and the ability to freely choose and to promote the person's own life and the lives of others. Therefore, describing the notion of dignity has shown a set of rights demanding respect for an individual's autonomy. The ethical principle of respect for autonomy as an integral part of medical care in the developed countries is addressed

in practice through informed consent, disclosure of information and truth telling, the ability to identify one's desires, and the ability to make rational and free decisions. Thus, the principle supports a broad set of rights that provides the normative basis from which oppression, and even the family use of power over vulnerable individuals have been opposed. However, in Islamic countries, people are more likely to defer to the physicians' opinions, as the culture is more deferential to authority and places a higher value on social harmony, or collective well-being, than on self-determination. To be a person is by definition to be capable of free and rational choice; such abilities provide the ethical foundation for the expression of uniquely individual beliefs, desires, preferences, and values. The chapter revealed that the diminished focus on the principle has been noticeable in medical and health care academic and public discourse as well. Academic education for a fuller account of the nature of autonomous moral agency is needed; this education would include a framework for interpreting what autonomy concretely means and for articulating the essential historical and social nature of persons by taking seriously the concrete developmental aspects of becoming and being a person, as well as the phenomenological reality of being an agent in the world of everyday life without embracing the notion that the ultimate source of value or authority is tradition or community. Islamic culture needs to look at the ethical principle of respect for autonomy as being independent, and as an individual's right that holds vital development for value, preferences, and decision-making, rather than just an approach copied from the west.

The fourth chapter presented a comparison between the ethical framework in Islamic countries versus the one found in Western countries, with focus on dignity and respect for autonomy of elderly health care. As shown in the study, Muslim people are theoretically

free to choose their medical treatment, but in practice the decision often goes to the family. Due to the cultural traditions of family relations and obligations, mutual decisions are often practiced and encouraged. The elderly patients' ability to decide for themselves is often undermined due to the family's view of ageism. This approach has violated the principle of respect for autonomy; physicians are relieved from the responsibility of respecting a patient's decision that might not be in the patient's best interest. In light of a lack of clear limits to the influence of the family on patient autonomy and a lack of minimum care standards that potentially compromise the best interests of the patient, Islamic countries' sociocultural framework and health care structure have contributed toward embracing a relational autonomy and a loss of individual autonomy. This ground of relational autonomy frameworks appeals to the importance of cultural ideals, as an ingredient in shaping and evaluating one's identity presents a potential damage to dignity and respect for autonomy for many elderly individuals.

Physicians should be obligated to have a discourse with elderly individuals first, and ensure that patients are aware of the informed consent content. Also, Living Wills can be explained as a tool that appoints someone to take care of the patient's wishes on later life issues, instead of the current blind view about the future and the risk that might be associated with such treatment in later life (life-extending treatment, extraordinary treatment, etc). The importance of informed consent needs to be emphasized and acknowledged; the concept of the Living Will that is uncommonly recognized in Islamic countries needs to find a path into Islamic countries health care to enhance the principle of respect for individual autonomy. Public awareness about having an advance directive should also be supported, to enhance knowledge and communication between specialists,

patients, and family. Educating health care providers about the concepts of dignity and respect for autonomy will lead to public awareness about respecting elderly people's wishes for their wellbeing in their earlier life as well as later in life. The examination revealed the need for research, education, and training of health care professionals on geriatric matters to meet today's challenges. The challenge is to ensure that health care providers have the proficiency to deliver care and treatment that maintain elderly people's dignity and respect their autonomy.

The fifth chapter justified respecting human dignity and personal autonomy to help improve elderly health care in Islamic countries. After providing several ethical approaches that have been implemented in the West to support both concepts of dignity and respect for autonomy within geriatrics care, the chapter showed that greater attention should be given to the responsibility of caregivers to enhance dignity and respect for autonomy for care of the elderly. The analysis implemented in the West would be of great help to elderly health care in Islamic countries. Islamic religious leaders should not be the only source of knowledge on elderly matters; geriatric specialists, ethicist, scholars, and the government should take up more responsibility on the topic. Significant attention should also be placed on educational establishments that will train professionals in the field of geriatrics. Media can have a major role in enhancing public awareness about the various options for care that are available for the elderly. The debate in society regarding sending elderly individuals to institutions will be a way of thinking differently about what elderly people need, and both ethical concepts should be respected and maintained. This change in point of view will eventually lead to the shift in the Islamic societies and will positively influence the overall health condition of the elderly.

In the Islamic tradition to honor and serve God, people must commit themselves to the Sacred Law, expressed in the Quran, the Sunnah, and Ijtihad. The fundamental principles of the Sharia involve preserving life, protecting freedom of belief, preserving the intellect, safeguarding honor and integrity, and protecting property. According to the discussion in the chapters, respect for a person's dignity and autonomy is grounded in a belief in the Creator. Protection of reason means that the integrity of human mental faculties must be preserved; that preservation is based on the consideration that rationality is what distinguishes man from the rest of creation, so at once a person's reason is lost, his or her humanness is lost.<sup>949</sup> Since health care interactions in Islamic countries involve religious worldviews, then considerations of aging and attitudes toward the aged should take into account these fundamental principles. It might be problematic to rely on religious texts for authoritative guidance on bioethical issues, but such texts may still be quite valuable in helping to articulate and think through our deepest feelings about human beings, their distinctive powers and activities, and the rights and responsibilities they possess. The ethical principles of respect for autonomy and dignity are a universal tool; it provides a method to resolve all moral issues in all areas of daily life, whatever the personal religions, philosophies, politics, cultural traditions and moral theories of the person involves.<sup>950</sup> It can also help health care providers bring more order, consistency and understanding of medico-moral judgments.<sup>951</sup>

Decisively, the notion of dignity is a universal equal value of all human beings to which are attached the specifically human rights. Regardless of what age a person is in, dignity and respect for autonomy should be a core value in health care practice. No one, because of age alone, should be deprived of the right to direct those areas of responsibility

he/she chooses to take on. Growing sensitivity to the ethical responsibility of each person to meet the elderly person's need to preserve dignity will help establish and keep open communication with the aging. Then the health care providers can even more effectively assist aged persons to live the rest of their life and exit it with a sense of dignity. Perhaps the greatest benefit of this insistence on an ethic of dignity will come not to today's aged, but to the current middle-aged generation, for they cannot escape the reality that they too will age and that when they are the elderly, the feelings they have shown toward aging will be reflected in their children's treatment of them. Geriatrics is becoming a part of the curriculum and thus of the language of medical education and standards of practice in Western countries. Graduate physicians are taking fellowship training in geriatrics, new geriatric programs are starting up, self-study and continuing education programs dealing with geriatrics are increasing, and students are learning geriatrics in their classrooms and on the institutions. A particular challenge in Islamic countries' health care is to transform the traditional care of health care providers, and society's views on the elderly for the sake of helping elderly people preserve a practical and sustainable dignity and respect for autonomy need to transform as well. Ethical practice requires that practitioners are careful not to err on the side of failing to take action to protect an elderly individual. On ethical and humanitarian grounds, changing attitudes to old age and devoting resources to older people is unquestionably the right thing to do.

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- <sup>947</sup> Betty J. Gale, "Advocacy for Elderly Autonomy: A Challenge for Community Health Nurses," *Journal of Community Health Nursing* 6, no. 4 (1989): 191-197.
- <sup>948</sup> Drew Christiansen, "Dignity in Aging," *The Hastings Center Report* 4, no. 1 (1974): 6-8.
- <sup>949</sup> Fazlur Rahman, *Health and Medicine in the Islamic Tradition: Change and Identity* (Park Ridge Center, IL: ABC International Group, Inc, 1998), 100-102
- <sup>950</sup> Rut Chadwick, Henk ten Have, Eric M. Meslin. *The SAGE Handbook of Health Care Ethics* (London, CA: SAGE, 2011), 22-23.
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